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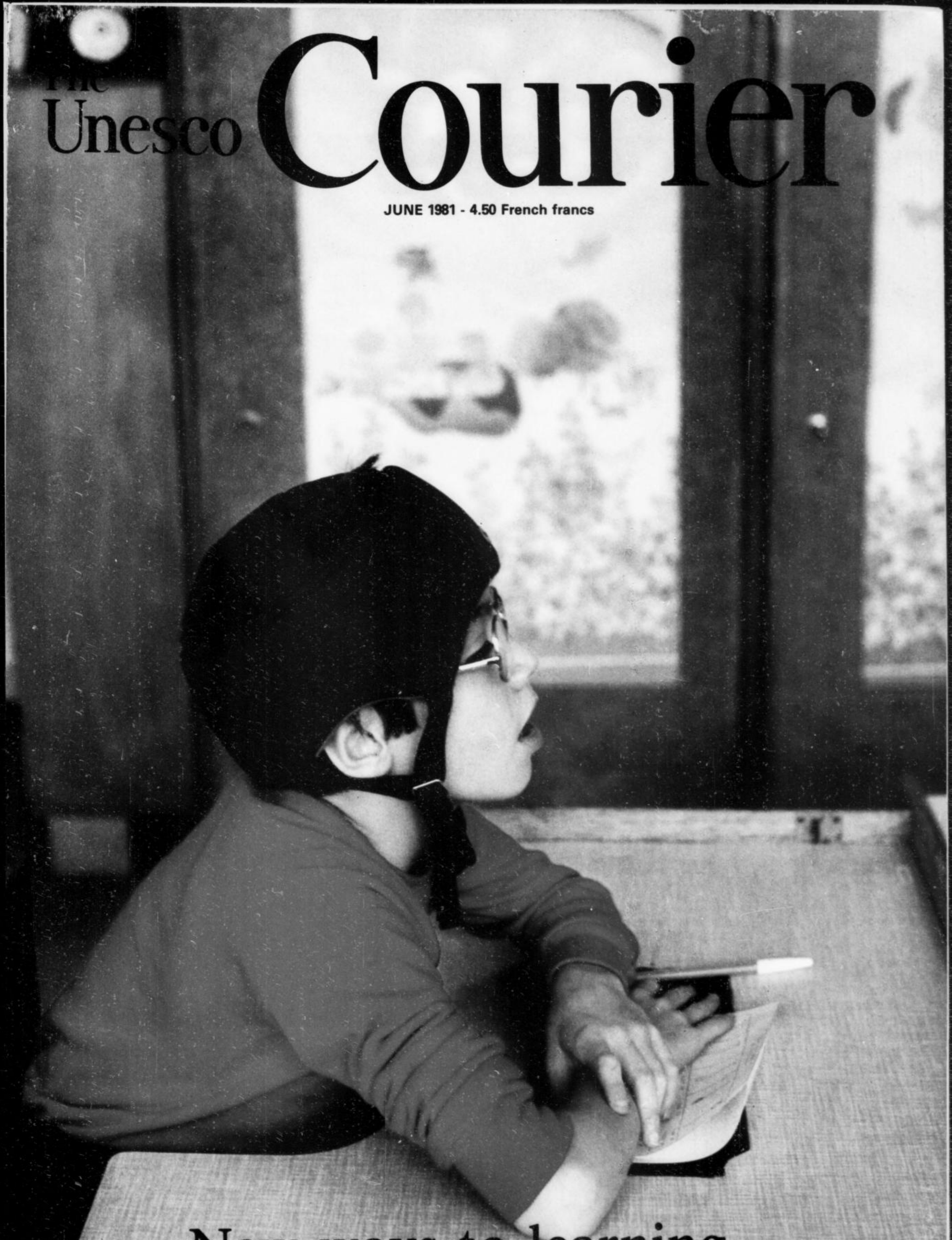

New ways to learning

INTERNATIONAL YEAR OF DISABLED PERSONS

Photo © Ethiopian Institute of Archaeology, Addis Ababa

TREASURES OF WORLD ART

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Ethiopia

Pre-Aksumite portrait

This bust is part of a limestone statue (82 cm high) unearthed at Haoulti in northern Ethiopia and probably dating from the 5th or 4th centuries of the pre-Christian era. The statue represents a seated woman with her hands on her knees, dressed in a long robe with narrow vertical pleats. She wears a wide three-stranded necklace, and her hair is depicted by rows of small lozenges. This portrait in stone dates back to a time when the influence of south Arabia, during the supremacy of the kingdom of Saba, is widely agreed to have been strong in this part of Africa where, some centuries later, the powerful kingdom of Aksum rose and flourished.

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A window open on the world

JUNE 1981 34th YEAR

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Cover

This issue, a follow-up to our January number, is largely devoted to the role of modern education in helping handicapped people to overcome the problems facing them in their search for full integration into society. Photo shows a physically and mentally handicapped child, wearing a protective helmet.

Photo Laurence Brun © Petit Format, Paris

SOS parents

Photo © Gilles Cohen, Paris

The decisive role of the family in rehabilitating handicapped children

by Leo F. Buscaglia

PARENTS are the most important and vital resource in the process of evaluating, educating, and rehabilitating a child with a handicap. Yet, for some mysterious reason, the child's parents are often seen as "the enemy". They are considered by many professionals as uninformed meddlers who are much too emotionally involved in their child's problems to offer even the simplest objective insight or positive action. They are, therefore, treated as secondary citizens in the diagnostic and re-educational processes, if not excluded altogether.

This is true, even though research findings consistently indicate that well informed, optimistic, accepting parents have a most positive and significant effect upon the education, well-being, and adjustment of their handicapped child. In the long run, their influence is far more productive and long-lasting than that of physicians, nurses, therapists, psychologists, or any of the many other helpers who will encounter the child in his lifetime.

It is, therefore, of monumental importance that parents and professionals strive to form a mutually beneficial partnership dedicated to the social, physical, psychological, and educational growth of the child.

The following four principles are offered as a possible guide to action designed to achieve this end.

- To begin with, the parents must be helped to understand their emotional and intellectual responses relating to their handicapped child, for these feelings may be preventing them from understanding clearly, and co-operating fully, in any therapeutic process.
- Parents must be offered an honest, meaningful, and accurate medical, social, psychological, and educational evaluation of their child's physical and emotional condition, and intellectual abilities.
- The parents must be given a thorough understanding of educational or rehabilitational programmes designed and recommended for their child.
- The parents must be encouraged to assume an active role in the re-education of their child and be offered a means for evaluating the effectiveness of the programme at every stage of its progress.

At best, it is not easy to be a parent. In fact, it is perhaps the greatest and most complex of human responsibilities. Yet, most of us are tragically unprepared for this demanding task. It is even more difficult to be the parent of a handicapped child, for birth is, in a very real sense, a gift. It is an awesome discovery to learn that one has produced an imperfect gift.

This realization often brings with it natural feelings of fear, pain, disappointment, loss, guilt, confusion, and general feelings of helplessness and inadequacy. Most parents have little knowledge of the conditions that provoke handicaps and few resources necessary to understand them. This lack of understanding can produce feelings which freeze them into inactivity, depression and self-recrimination, and prevent them from dealing adequately and productively with their handicapped child.

It is, therefore, inconceivable to expect that parents can immediately accept the birth of their handicapped child and be ready to help in the educational process. They must first be encouraged to understand that their feelings are appropriate, that it is understandable that they should be feeling a sense of disbelief and depression; that it is acceptable that they are in emotional pain, questioning and fearful; that they would like to wish it all away; that they should curse the fates that brought them this "misfortune".

At this point it may be impossible for parents to imagine that there is anything positive about a handicap. It is only with time, insight and re-education that the parent can be shown that whatever is positive is to be found—not in the handicap—but in the child who is handicapped. Their child is a child like other children. But he or she is also a unique creation, a combination of not only what there is, but also a limitless possibility of what, with their active participation, can be. So, the first step in the rehabilitation process lies in emotionally aiding parents through their incapacitating feelings, on to acceptance and active participation.

Professionals often feel that it is a waste of their time and energies to give medical, psychological and educational information to parents. After all, they state, it takes years of training to prepare a professional. Their argument is usually that parents would not understand the problem anyway, and a little knowledge is a dangerous thing. To know "the facts" would only confuse and frighten them more.

Nothing could be further from the truth! Knowledge and understanding are great eradicators of fear providing that the information given is not shrouded in mysterious medical jargon or half truths or uncomfortable pronouncements. What information is given must be honest, gentle, straightforward, and clear. In addition, diagnosis ▶

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often is nothing more than a statement of what is wrong with the child, what the problems are, the skills that cannot be performed, the abilities the child does not have. It is no wonder that parents leave such an experience in pain, bitterness and pessimism.

A real diagnostic presentation must be equally concerned with what the child can do, at what levels he is able to function, those aspects which show promise and where the strengths lie—for it is with these positive aspects that the therapeutic programme can be actualized. In her book, *The Siege,* Clara Clarborne Clark describes the results of such a diagnostic interview following months of tests and examinations of her autistic child. She says she needed information and techniques and the professionals gave her none. "I needed references," she continues, "I needed to know all about my daughter Elly, because whoever else may or may not work with her, her main therapist is me."

Too many professionals, because they often feel a general discomfort and inadequacy when faced with the human problem of talking to parents about their children's handicaps, hide these inadequacies in test results, complicated medical case histories, mysterious labels and high-sounding jargon which only serve to leave parents feeling abandoned, confused, and more fearful and despairing than ever.

Parents must be given the facts, for the facts will free them and bring them the necessary sensitivity and wisdom which will lead them to acquire the realistic skills necessary for their participation in their child's education and growth. The facts will offer them the resources to see and understand their child in a realistic fashion and make them a more knowledgeable and comfortable part of the rehabilitation team. Professionals must realize that no matter how many trained individuals work with the handicapped person in his or her lifetime, none will have more consistent contact, or a more significant and lasting effect than the parents.

The rehabilitation and education programmes for the disabled require the best possible interaction between and the participation of many individuals. Depending upon the disability, expertise may be needed from general physicians, neurologists, psychologists, occupational and physical therapists, educators, language and speech pathologists, and a variety of others. But the individuals who give significance and purpose to this process, and are at the core of it, will always be the handicapped individual and the parents.

It is therefore imperative that the parents thoroughly understand whatever remedial plans are designed for their child. Yet when parents bring their handicapped child to hospital for consultations or therapy sessions, which could be great educational experiences for them, they are more often than not asked to "wait outside". If they ask questions they are often put off or embarrassingly talked down to. The inference is that information on their own child is private and none of their concern, that they are too ignorant to understand it even if it were explained. It is no wonder, therefore, that parents of the handicapped so often express feelings of isolation, inadequacy and impotence.

To exclude parents from the educational planning for their child, as is so often the case, is both ludicrous and counter-productive, for no one has a greater need to understand the child than its parents. It is they who will experience the daily progress or lack thereof. It is they who will observe and aid their child through pain and tears as the child battles his or her way through the therapeutic programme. Professionals must understand that parents may not be perfect, they may not always know or do "what they should know or do", but nonetheless, they will still have to understand and do more than anyone else. For who else will be spending more time and energy in permanent, everyday contact with the child?

Parents are more than willing to take an active part in their child's remedial programme and will carry out their charge with the tender loving care and consistency that most professionals do not have time for. It is logical that since they will be doing something anyway, they may as well be doing the right thing.

It is important not simply that parents be given time to work through their feelings,

A young handicapped girl learning to walk at a centre for the disabled in Lesotho, southern Africa.

Photo Martine Frank © Magnum, Paris

that they be given accurate information and made integral partners in the planning of the programme for their child, they must also be encouraged to do something tangible and positive with the strength and information they have acquired. Knowing is a beginning, but the true value of knowledge lies in its daily application.

The rehabilitation process is a long, arduous, demanding journey through which the parents must be supported and advised. They will be required to learn how to schedule their time so as to be able to meet their child's needs, without giving up their own personal physical, psychological and intellectual requirements for growth. I have known parents who have not had time for themselves in all the years since the birth of their handicapped child. They cannot even obtain the help of baby-sitters who often, due to their fears or lack of information, are reluctant to take responsibility for handicapped children.

Parents will have special motivational problems, for the rehabilitation process is often slow. So much expended energy on their part often seems to produce so few tangible results and so little progress. They will have to be given the courage to continue. In addition, they will have to learn how to cope with the problem of rejection by society.

As part of the team they will need to know precisely what they can do for their child, what realistic demands can be set, and what possible limitations there are. They must be helped over feelings of inadequacy and imperfection as they involve themselves in the learning process. They must be made to understand the fact that they are not expected to be perfect but rather, only human—that, perhaps, their love, concern and humanity are their greatest assets.

If these conditions are adhered to, a bridge between parents and professionals can be constructed over which the handicapped child may be guided to independence, growth, security and self-esteem.

What is needed is a bill of parental rights regarding parents' partnership with professionals in helping the handicapped child. It may be stated as follows:

- Parents have a right to take the necessary time to deal with the myriad confused and painful feelings associated with giving birth to an exceptional child.
- Parents have a right to sound medical, psychological and educational knowledge regarding their child's present condition and future possibilities.
- Parents have a right to a clear understanding of their specific role in meeting their child's unique needs.
- Parents have a right to participate in the programme of remediation and re-education of their child.
- Parents have a right to periodic re-evaluation and involvement in the continual planning for new goals which may be required as a result of time, maturation and new findings.
- Parents have a right to information regarding available community support systems to meet their financial, intellectual and emotional needs.
- Parents have a right to some interaction with other parents who have handicapped children so that they may share feelings, hopes, and general human considerations as they meet the challenge of raising their handicapped child.
- Parents have a right to develop in their roles as persons, apart from their role as parents of a handicapped child.

Given these rights, parents grow to become real assets in the rehabilitation and education of their handicapped child.

As one parent of a handicapped child wrote, "You wake one day to realize that all the trials, the turmoil, the anxiety, the fear have given you a modicum of that which you sought—understanding. You find, somewhat to your surprise, that the lessons you have learned are priceless. Although you have sometimes rebelled against it all, questioned it, resented it, you would not relinquish these lessons. For you have begun to acquire that depth you have long sought. Your experiences have brought you into closer touch with others. Therein lies the victory for you. Therein lies your ability to appreciate your child. If the child can understand that you have grown to this conviction he or she will feel freer, not a burden to you or anyone, not a pulling-down element in your life but an uplifting one. If the child can understand that, then he will know he has given you the opportunity to grow with him. And the growing process will continue onward. The possibilities are endless. Isn't that what it's all about?"

To this, I can only add, "Yes—that is truly what it is all about!"

■ **Leo F. Buscaglia**

An African approach

by Gustave-Justin Nlo

IN traditional African society, care is lavished on the mentally handicapped child, who is brought up and taught by its mother and father. The youngster will be given a taste of work in the fields (with the cacao trees, groundnuts and maize), of household jobs (drawing water at the spring, splitting logs, fetching wood from the bush, washing clothes and utensils), or he may learn the rudiments of a craft. He will be initiated into traditional rites, take part in funeral ceremonies, palavers and confessional assemblies.

If the child is seriously handicapped, the family will do the best it can to educate him and give him the utmost help and support in the home.

In the rural areas the mentally handicapped child has always been a fully accepted member of the African extended family, that expansive unit whose hospitality is not confined to father, mother and children but encompasses aunts, cousins, and uncles. Since one advantage of the extended family is that all its members feel an acute sense of their responsibilities to each other, the handicapped child can find food and lodging in every household in the village. He gives a helping hand to all and sundry and is cossetted in return. Everyone in the village stands by him, for his fate is not solely the concern of his father and mother.

The village faces many problems when it comes to his schooling. Specialized institutions are few and far between, and in such schools as exist in the vicinity no one will agree to take him on because he will be a nuisance during lessons. Only in rare cases will the family be able to afford to send him to a specialized institution in town; and so he will usually have to stay in the village.

As a rule, the children's handicaps are detected by specialists during informal consultations, at school, and in child- and mother-care centres.

Some families are ashamed to tell the truth about their child because a preliminary examination may diagnose his handicap as due to some such cause as chronic alcoholism or a hereditary defect. However, such information must be noted if the teachers are to receive reliable information about the child.

When a child has been accepted by a centre, most parents expect to see him miraculously transformed into someone who can be reintegrated into the productive world, whereas in most cases his "normalization" can only be partial.

In any case, the role of the institution is complementary to that of the family, which must give regular support to the teachers. It is in collaboration with the teachers, for example, that the family will encourage the youngster to take up a craft for which he shows a special aptitude, such as carpentry, basketwork, pottery, sewing, farming or gardening. Then, when the child is properly apprenticed, those concerned with following his progress will advise the parents how to help him make his way in working life, for the support of the family will continue to be the mainstay of his integration into the modern world. ■

GUSTAVE-JUSTIN NLO, *of Cameroun, is secretary-general of the Association of Parents of Handicapped Children, in Yaoundé.*

Their handicap is hunger

IN any consideration of the plight of the handicapped, one simple truth should never be forgotten: a large proportion of the handicaps with which they are afflicted could be prevented if the millions of starving and malnourished people in the world were given an adequate, balanced diet.

In a world in which man is capable of reaching the moon, hunger is a scandal which every year causes untold numbers of deaths among the poor of the Third World and leaves millions more marked for life by severe physical and mental impairment. Of the 450 million handicapped people in the world, therefore, a large proportion owe their disability entirely to malnutrition.

In the *Preliminary Assessment of the World Food Situation, Present and Future,* published by the United Nations in 1974, it was estimated that "in the Far East alone more than 100,000 children go blind each year due to vitamin A deficiency... Iron and folate [a vitamin of the B complex] deficiency anaemias are widely prevalent in developed and developing countries and are the cause of ill-health and result in a decreased ability to lead an active life... A comprehensive world review of endemic goitre revealed that there were 200 million people suffering from the disease...which is usually accompanied by endemic cretinism... Half the children under five in developing countries are inadequately nourished, and for many this will inevitably lead to premature death". The *Sixth Report on the World Health Situation,* published by WHO as recently as last year, confirms the gravity of the problem.

Vitamin A deficiency is one of the most elementary forms of malnutrition and one of the easiest to combat. The 1974 United Nations World Food Conference, in its second report, stated that "considering each child

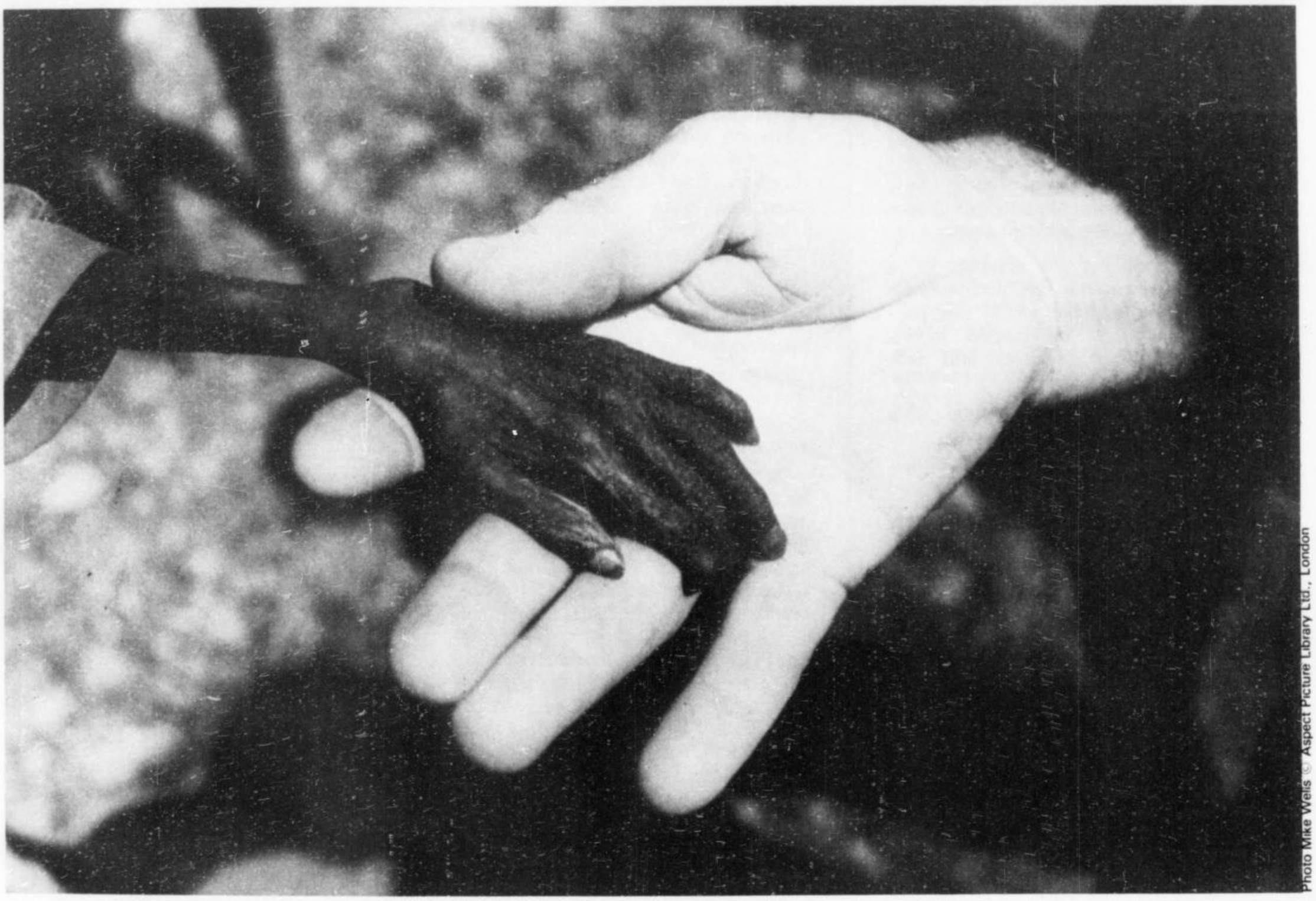
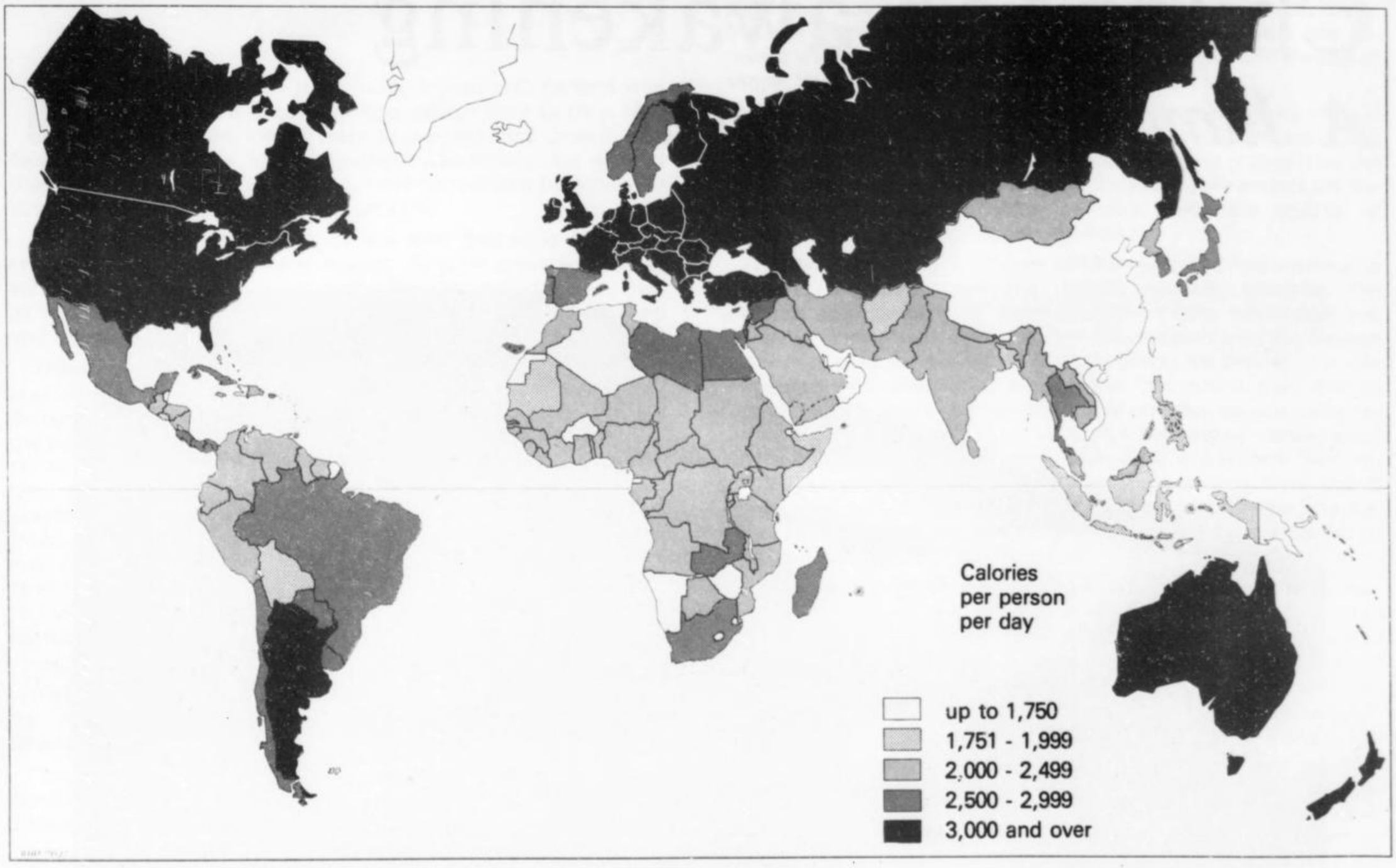


Photo Mike Wells © Aspect Picture Library Ltd., London

World food map: dietary energy supply (per capita), around 1975



Source: World population data sheets, 1975 and 1978, Population Reference Bureau, Inc., reproduced in the *Sixth Report on the World Health Situation*, Volume I, World Health Organization, Geneva, 1980. No official data available for China.

has to be given two capsules [of vitamin A], the total annual cost of protecting 100 million one-to-five-year-old children all over the world against the risk of xerophthalmia (caused by vitamin A deficiency) would be around three million dollars." In other words, with just three dollars, one hundred children could be insured against the risk of blindness, an infinitesimal sum when compared with the enormous amounts spent on armaments.

One essential aspect of malnutrition as a source of handicaps is the effect it has on the brain of the infant both before birth and during the early years of life. Protein-calorie deficiency, the cause of maladies such as Kwashiorkor and Marasmus which decimate the infant populations of the poor countries, combined with lack of a stimulating environment, is the chief cause of retarded development and brain damage.

The problem begins with the mother. A malnourished mother is unable to supply the unborn child with the nutrients essential to its proper growth. Mothers whose diet during pregnancy has been deficient in protein and calories often give birth to children of below average weight and with smaller than average brains.

Recent medical findings have confirmed the relationship between low birth weight and mental retardation. It has been shown that less than one per cent of newborn children of normal weight suffer from mental deficiency as compared with fifty per cent of those who weigh less than one and a half kilos at birth. Malnutrition has similar effects during the first five years of life, the most important period for human brain growth.

A large proportion of the victims of malnutrition, and this includes the majority of the children of the developing world, will suffer all their lives from irreversible disabilities—problems of sight and hearing, motor defects, epilepsy, cerebral palsy, etc. The result is mental retardation and stagnation of the faculty of comprehension, with all the dire consequences for later life that this entails (failure at school, inability to learn a trade, failure to adapt normally to society).

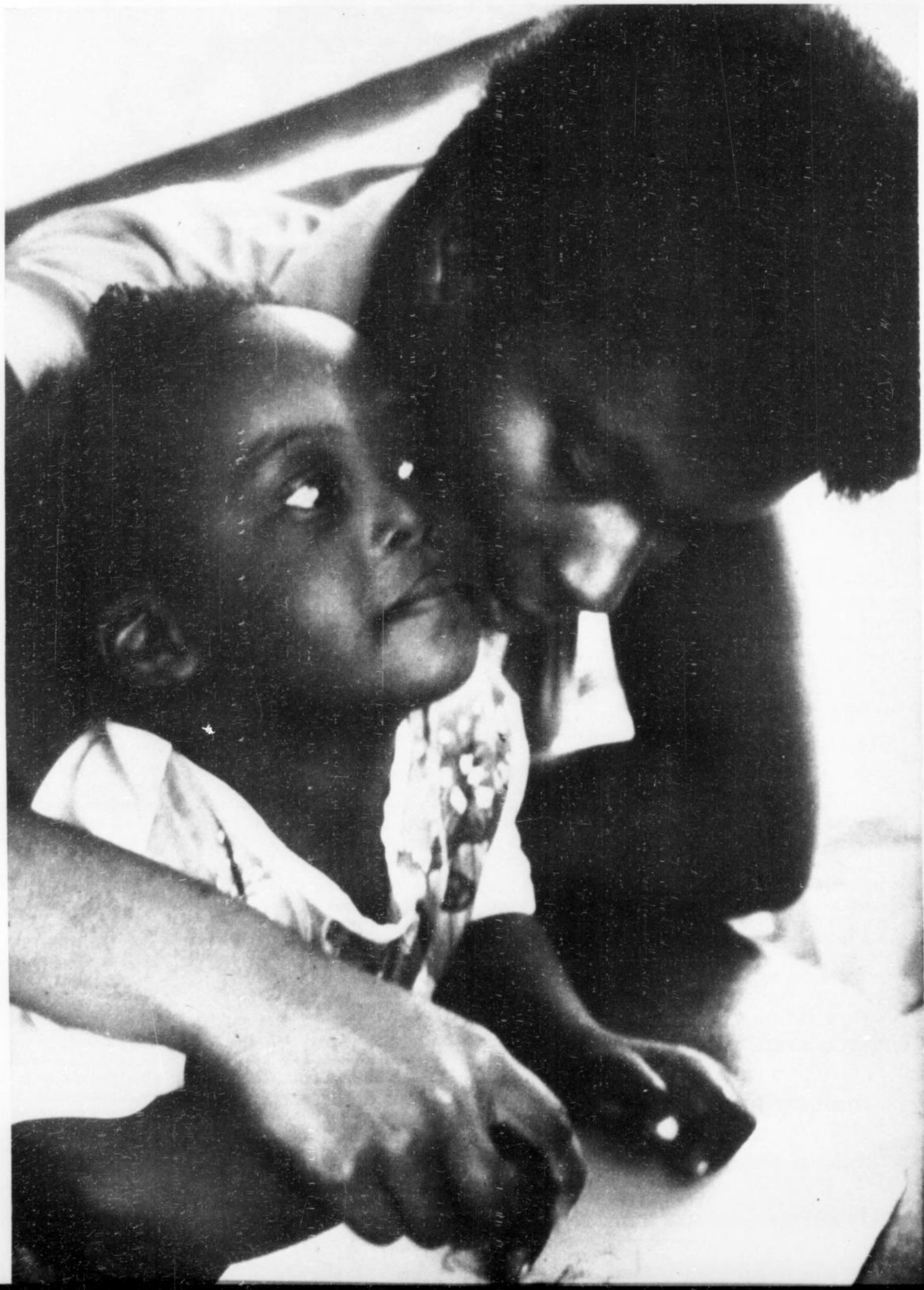
Seen against this background, it becomes clear that the great effort that has been made over the last few years by the United Nations and its specialized agencies, such as Unesco, to achieve a new world economic order is also, in effect, the most important step forward ever made towards the prevention of handicaps resulting from malnutrition. ■

A Unesco enquiry on malnutrition and child welfare

Under its *Research and Human Needs* programmes Unesco has launched a research project aimed at improving our understanding of the effects of malnutrition on young children. The project is based on four countries of the Mediterranean but there are plans to extend it later to other regions in Africa, Asia and Latin America. The objectives of the research project are to identify and evaluate the nutritional, biological, environmental and other requirements of infants, young children and pregnant and nursing mothers and to propose and promote effective measures to be taken within a given social and cultural context. The research will be undertaken by teams of local scientists in collaboration with Unesco and various scientific organizations and will cover many fields including nutrition, biology, chemistry, genetics, neurophysiology, sociology and cultural anthropology.

Childhood awakening

A Jamaican experiment



Photos Unesco. From a slide presentation of a Unesco project on "Innovative information and examples of good practice in education of the handicapped"

by Marigold Thorburn

THOSE of us who grew up in loving homes with parents who played with us and gave us toys seldom stop to think how important these things were to our eventual growth and development. Yet they are of enormous importance, for without them we learn slowly, if at all. If you have no toys as a baby how do you learn to focus on an object or grasp it?

It was to remedy situations of this kind that early childhood stimulation programmes were devised. In poor countries lack of stimulation is more often due to lack of knowledge and poverty than to deliberate neglect, but the result is the same —children are slow and regarded as dull when in fact they are merely uninformed.

There are, of course, other causes of delayed development, for example, a disability due to illness or brain damage. In these cases doctor and therapist have to work very closely together and obtain the enthusiastic co-operation of the parent, grannie, auntie or other parent substitute. The parent has as much to learn as the child; he or she needs to understand that handicapped children are not necessarily helpless or dependent and that given more attention and training results can be achieved that make the extra effort involved well worth while. When a child suffers from both parental indifference and malnutrition, the health and social welfare workers have to make a special effort to rouse the interest of and motivate the parents. In all these situations education is the key.

The Jamaican Early Childhood Stimulation Project is a continuous remedial action programme designed to meet the individual needs of the child and to arouse and hold the imagination of the parent, usually the mother, and get her involved in the learning process.

The Jamaican project is based on a North American model modified to fit local needs and resources. It consists of four main stages.

First, the children needing help have to be identified. Mothers, members of the family and friends are often the first to recognize that a child's development is slower than usual. The most common signs are lateness in sitting, walking or talking. Sometimes a doctor or nurse on a routine visit to a clinic notices the tell-tale signs of late development. In other instances late-developing children are detected by means of simple tests carried out in day nurseries and crêches. In all these cases children can be brought to our offices for confirmatory checks and examinations.

At the second stage, if a child is found to have a significant delay in development, a further in-depth assessment, including the establishment of a full case history and a complete medical examination, is carried out in our offices. On the basis of our findings a programme of treatment and intervention is drawn up.

During the third stage this programme, which consists mainly of various forms of teaching and training, is put into practice in the child's own home. One very important aspect is that the mother becomes fully involved in the programme and herself carries out the teaching at home in between the weekly visits of the social auxiliary.

The final stage involves a review and evaluation of the child's progress. The mother brings the child back to our offices once every three months or so for this reassessment and, if necessary, the programme can then be adjusted.

The Jamaican project is supervised by a public health service nurse, but this task could be carried out by anyone with the appropriate training and experience, such as a teacher or a social worker. Identification of children in need of help is the responsibility of specially trained workers of the Jamaica Youth Corps. Assessments are made with the help of the Portage Check List, a systematic, sequenced list of child behavioural skills and aptitudes, each aptitude on the list corresponding to a specific item of the education programme. In this way the child, the mother and the social auxiliary form a mutually dependent team.

In Jamaica, the auxiliaries, known affectionately as "Crashies" because they had been through an accelerated training or crash course, were selected from participants in a special employment programme. In the new project being carried out in St. Catherine the auxiliaries have been recruited from the local communities and the parents themselves are also being trained.

MARIGOLD THORBURN, *of Jamaica, is regional co-ordinator with the Caribbean Institute on Mental Retardation and Other Development Problems, at the Northern Caribbean University, Kingston.*

This innovation has worked well and each auxiliary visits about a dozen homes a week. The auxiliaries work under the guidance of a supervisor but it is they who keep in touch with the mothers. Medical assessment is undertaken by a doctor. Exercises and activities are specially developed for each child and involve the use of simple toys, often made from waste materials.

In 1978, five years atfter the Early Childhood Stimulation Project started in Kingston, we decided to take a look at what had happened to some of the children who had participated in the project from the very beginning. Half of them were still involved in the project and the remainder are attending either ordinary elementary schools or special schools for handicapped children.

The progress made by fifty-six children who had had continuous care over a period of eighteen months was also assessed. The children were divided into three groups— mildly, moderately and severely handicapped—and progress was measured by the average number of skills learned by the children during the period. This was compared with what would be expected of a normal child. Over a given period of time a normal child would probably learn six skills per month. We found that the mildly and moderately handicapped children gained 50 per cent more skills than would have been expected in normal children. The children of the severely handicapped group, however, did not do so well, but they nevertheless acquired more than twice as many skills as they would have been expected to learn without any stimulation.

Many medical conditions can cause delays in development, retardation and other types of handicap. Among the commoner ones found in our project were Down's Syndrome, brain damage due to complications at birth, jaundice after birth, meningitis, epilepsy and rubella contracted by the mother during pregnancy. In almost one fifth of the children seen it was impossible to determine the cause of handicap.

In almost all these conditions early stimulation can produce remarkable results and it is anticipated that, in the long run, children who have benefited from early stimulation programmes will meet with fewer problems in their education and have better prospects of achieving independence in their adult life. Furthermore, seeing the improvement in her child, the mother becomes more optimistic about its future. The combination of loving care and well planned stimulation can, therefore, produce real progress.

There are still those who think that it is too expensive and, indeed, scarcely worth the trouble to provide help for children with delayed development. In Jamaica we have shown that the cost per child can be remarkably low (280 Jamaican dollars per child per year), that there is no need for highly specialized staff since ordinary, well-motivated, intelligent people can be trained for the work involved, and that, with proper care and attention, children with delayed development can become happy, useful, productive and independent adults. ■ **Marigold Thorburn**

The Jamaican Early Childhood Stimulation Project for children with delayed development relies for its success on close teamwork between the child, the mother and the social auxiliary (below), backed up by the doctor in the clinic. The auxiliaries visit the children's homes once a week, but between visits the mothers themselves continue the programme of educational stimulation and training (opposite page).

Photo Unesco

Unesco and special education for handicapped children

Photo Eduardo Gajeiro, Unesco

A large proportion of the population in all countries (10 to 15 per cent) is affected by handicaps, whether sensorial, motor or mental, which limit their capacity to benefit from an ordinary education. The handicapped require an education adapted to their potential, their capabilities and their needs—"special education" as it has come to be called—which will enable them to develop their skills in order to become full members of the society to which they belong and to achieve personal development towards independence.

Special education is thus the educational component of rehabilitation. It is needed for all those individuals who experience or are at risk of experiencing significant and continuing difficulties in learning and in adjusting to normal educational opportunities made available to other persons.

It need hardly be said that special education has always been a matter of prime interest to Unesco, an interest that was underlined in 1966 when at its 14th session the General Conference of Unesco authorized the Director-General to "develop a programme in special education for handicapped children and young people on the basis of voluntary contributions from Member States."

Since then significant advances in teaching techniques and important innovative developments have taken place in the field of special education, particularly during the past decade, and much more can be achieved in the teaching of handicapped persons than was previously thought possible. Many of these advances in teaching techniques can be adapted to the needs of developing countries with limited reserves of materials and personnel.

In the light of these developments the General Conference of Unesco, at its 20th session held in October-November 1978, instructed the Director-General to "formulate, with the assistance of outside experts, a comprehensive, long-range programme of action designed to enhance the rights of all handicapped persons to an appropriate education which meets their needs and aspirations".

As a first step an international meeting on special education, attended by experts from fourteen countries, was held at Unesco headquarters in Paris in October 1979. The experts drew up a statement of principles by which Unesco's programme should be guided.

Reaffirming the right of every child to an education, the experts declared that the purposes and goals of education were essentially similar for all children, even though the techniques required to help individual children progress might be different. Some children would require substantial modification of the educational programme while the needs of others could be met by only minor variations. Educational resources for handicapped students should be comparable to those available for other students and appropriate to meet their special and often long neglected needs.

The experts pointed out that while special educational programmes would necessarily entail additional expenditures and each nation was faced with the fact that it had insufficient funds to meet all its purposes, the costs of failing to provide early identification and education of handicapped children and subsequently to train those children and place them in the work force were much greater. Studies of rehabilitation and education programmes across the world showed that the economic advantages from such programmes in productivity, payment of taxes by handicapped persons and reduced need for welfare assistance and disability stipends, outweighed the costs. Failure to educate and train handicapped persons in proportions equal to the provisions of services for the non-handicapped, because of the problem being perceived as a lower priority, resulted later in expensive programmes to care for the untreated disabled. Developing nations, as they formulated new approaches to educating children, should be aware of the problem other nations had had

WORLD CONFERENCE IN MADRID, NOVEMBER 1981

How can physically and mentally handicapped persons best be given the opportunity to become involved and integrated into daily life as independent and productive members of their communities? This question, together with the problem of the prevention of handicaps, will be the focus of discussion at a major international conference to be held in Madrid later this year, from 2 to 7 November. The conference is being prepared by Unesco in collaboration with the Spanish Government and with the help of the competent intergovernmental and non-governmental organizations (especially the United Nations, the World Health Organization, the International Labour Organisation and the United Nations Children's Fund). The Madrid Conference will be multidisciplinary in nature and will provide a forum for a wide exchange of experience, views and information on the present state of education for handicapped people and an occasion on which "the main lines of international action in favour of special education and in favour of prevention, of re-education and of assistance for the physically and mentally handicapped will be studied and defined".

Photo Laurence Brun © Petit Format, Paris

in following this approach of giving a low priority to the handicapped.

Special educational services should, the experts declared, be tailored to meet the assessed and agreed needs of the individual student and should lead to clearly stated curriculum goals and short-term objectives which should be regularly reviewed and where necessary revised. They should be within reasonable travelling distance of the pupil's home or residence except in special circumstances where the pupil's needs could not be met by these means. They should be comprehensive, serving all persons with special needs irrespective of age or degree of handicap. No child of school age should be excluded from educational provision on grounds of severity of handicap or receive educational services significantly inferior to those enjoyed by any other student. They should offer a range of choices commensurate with the range of special needs in any given community.

The experts devoted part of their discussion to the question of the integration of the handicapped into the normal educational system, a matter about which there is still considerable controversy, which is reflected in the articles on pages 16 and 20 of this issue of the *Unesco Courier*.

Special education programmes would in the future be found in a variety of settings, with some disabled children able to participate in a regular school setting, while others would require very intensive programmes. There should be, as a basic assumption underlying educational and other efforts on behalf of the handicapped, a commitment to integrating the disabled person as fully as possible into the community of non-handicapped persons. History was replete with examples of unnecessary segregation of disabled, and consequent substandard treatment and discrimination.

Integration of the handicapped into the normal educational system was an increasingly common practice. Short - and long-term studies showed that achievement among handicapped people who were educated in a specialized setting was no greater than that of those educated in regular classes. The special class or school tended from the outset to take a pessimistic view of the pupils' potential, which undermined their chances since they were inclined to conform to this pessimistic image.

It was necessary to stress the positive advantages of integration. With integration there was less need for costly special building and additional highly specialized staff; in developing countries, educational facilities were extended to more children; a handicapped child adapted more easily to living in ordinary society the earlier he or she began to do so; the non-handicapped grew up with the handicapped and learned to accept them and their disabilities from the beginning.

The experts pointed out, however, that integration was not the answer to every problem and it did not mean the mere physical placement of handicapped children in ordinary schools. It required very careful planning and preparation of teachers, and the development of support services.

Care should always be taken to ensure that integration was in the best interests of the child. For this reason the needs of each individual child had to be considered, and decisions made as to what type of educational provision, given the options available, would best suit him or her.

Finally, the experts stressed that, in view of the discrepancies in types and degrees of handicaps as well as the diversity of conditions in different countries, there was a need for a variety of appropriate educational provision for handicapped children; some might need special schools, others separate programmes for part of the day or for certain periods of their lives, while other children could profit from a regular classroom with some extra periods of instruction or help. Countries would have to study what was best suited to their conditions and develop their strategies accordingly. ■

Photo La Nacion-Unesco

ACCESS TO WORKS PROTECTED BY COPYRIGHT

In line with objectives of the International Year for Disabled Persons, Unesco has taken steps to facilitate access by disabled persons to works protected by copyright.
A request has gone out to Member States to help meet a pressing need in developing countries for printed works and audio-visual materials. Assistance is also being sought in arranging for the holders of copyright to assign the reproduction, translation or adaptation rights for Braille publications and audio-visual materials designed for handicapped persons on preferential terms to publishers in developing countries.
A second programme has been undertaken jointly with the World Intellectual Property Organization (WIPO) in co-operation with the World Council for the Welfare of the Blind (WCWB). States party to the two major copyright Conventions, the Universal Copyright Convention and the International Convention for the Protection of Literary and Artistic Works, administered respectively by Unesco and WIPO, have been asked to consider questions relative to the free flow of recorded and embossed reading materials for blind and physically handicapped readers. Comments on a study prepared by the WCWB will be used as the basis for recommendations aiming to define and harmonize international co-operation and provide the widest possible access to materials for the visually handicapped. A similar study is being undertaken regarding the problems facing the hard of hearing in co-operation with the World Federation of the Deaf.

INTERNATIONAL RESPECT FOR THE RIGHTS OF THE DISABLED

What legal protection is offered to handicapped children by existing international instruments? The answer to this important question can be found in **La protection des Droits des Personnes Handicapées par Différents Instruments Internationaux** ("The Protection of the Rights of Handicapped Persons by Different International Instruments"), which is being published (in French) by Unesco later this year. (An abridged version in English is in preparation). Most international organizations have long been concerned, each in its own field of competence, with promoting the rights of handicapped children. But the texts they have produced are scattered as to their sources and of variable legal value. The Unesco publication presents analytical assessments of international texts relating to the handicapped child in the fields of civil, economic, professional, social and family life. Through this work Unesco is seeking to persuade governments to ratify existing conventions and to respond to the need to generalize these rights in a single international convention. Left, handicapped persons demonstrate in defence of their rights in Costa Rica.

Photo © Bester Kanyama, Salisbury

UNESCO'S CO-ACTION PROGRAMME AND THE INTERNATIONAL YEAR OF DISABLED PERSONS

Unesco's Co-Action Programme, which offers individuals, groups and institutions the opportunity of participating in self-help community projects throughout the world, has decided, during the International Year of Disabled Persons, to concentrate its efforts on providing much-needed equipment and training facilities to schools and centres for the handicapped in the developing countries. Photos show three of the many schools and centres receiving aid. Above, the Waterfalls Centre, Zimbabwe, for children suffering from cerebral palsy; below left, the Centre for Special Education at Chimbote, Peru, a school for blind and deaf children and for children with speech and learning problems, as well as those suffering from multiple handicaps; below right, the Sri Sangwal School, Thailand, which accepts physically handicapped children from kindergarten to tenth grade. All these establishments are in urgent need of funds and Unesco receives fresh requests for help every week. Anyone –individuals, groups, institutions–can help, either by sending a donation in support of a particular project (Unesco will supply a list of all the projects in hand) or by making a contribution, however small, to Co-Action's General Fund. Administrative costs are borne by Unesco and the entire sum sent will go to the project. You can also correspond directly with the people running the project (Unesco will supply the address). Donations, as well as requests for further information, should be sent to: Unesco, Co-Action Programme, OPI, 7 Place de Fontenoy, 75700 Paris.

Photo © Centre for Special Education, Chimbote, Peru

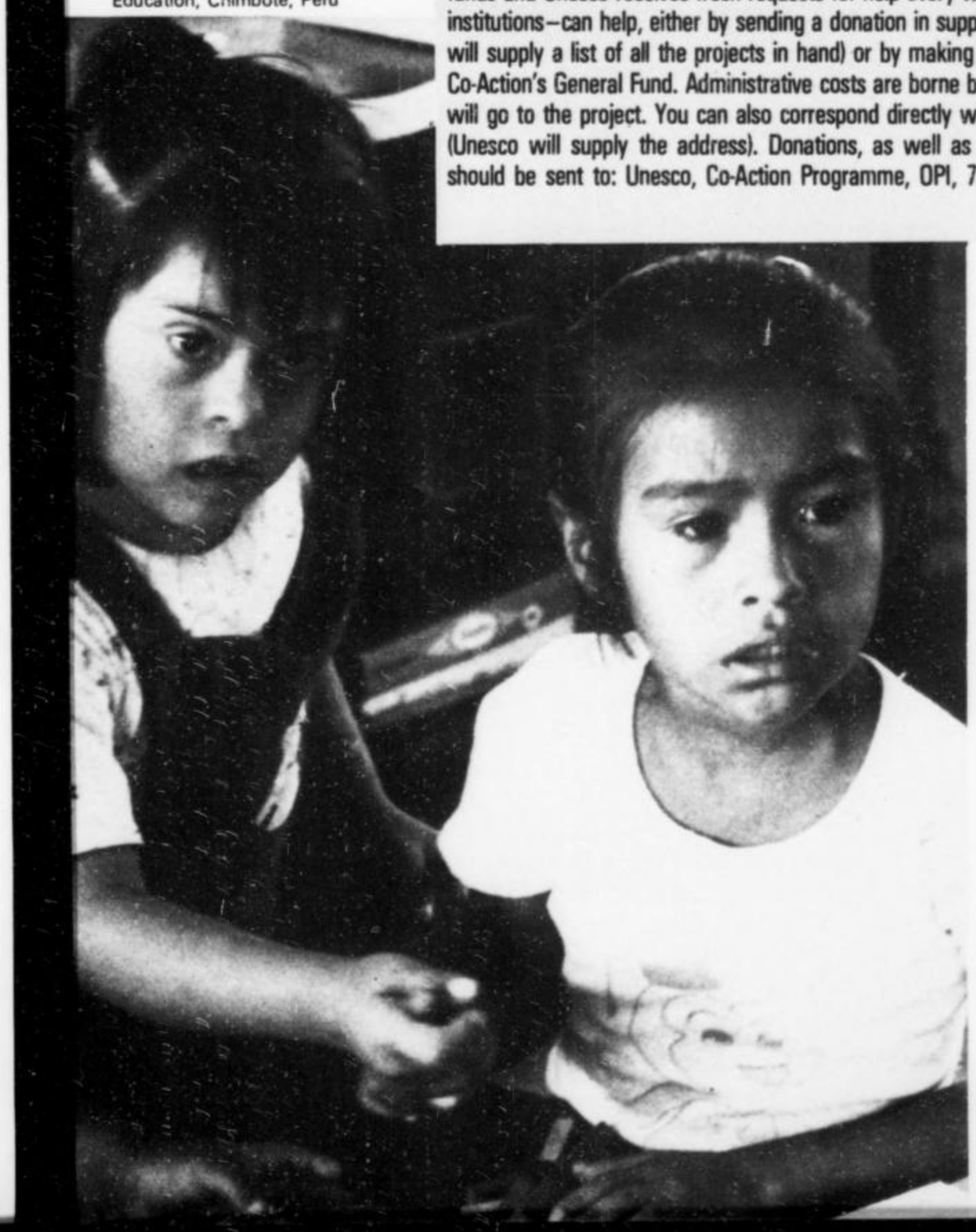
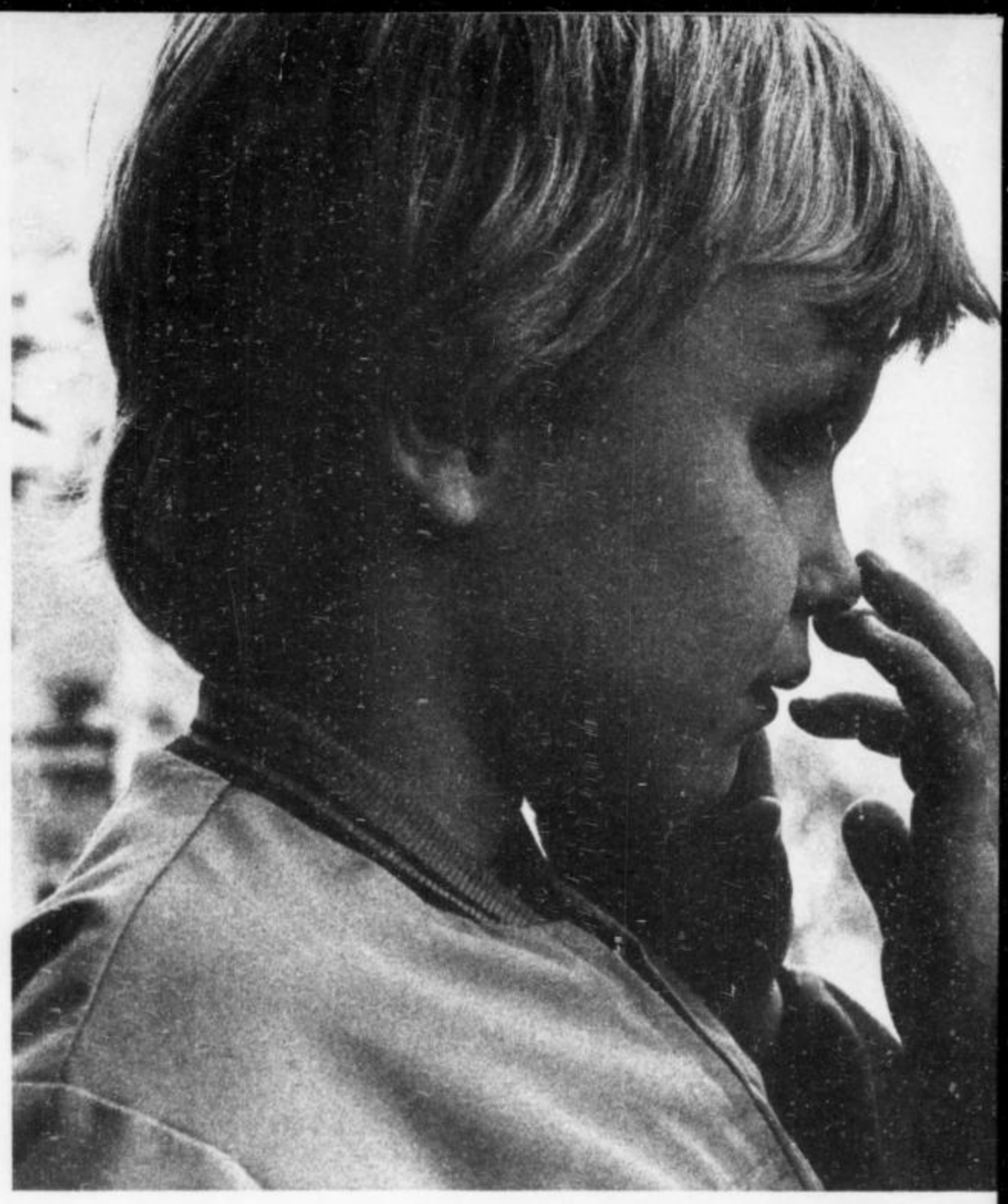


Photo Sudchit Bhinyoying, UNICEF

Special schools or integrated education?

I. 'The integration of the handicapped into society can be best prepared in special schools'



by Vladimir I. Lubovski

INTEGRATION is one of the most frequently discussed problems of special education. The integration of handicapped children into the normal education system has many supporters both among workers in the field of special education and (especially) among the parents of handicapped children, who are attracted by the thought that their child will not be set apart in a special group among his normally developing contemporaries.

At the same time, it must be said that an over-simplified conception of integration—an indiscriminate, superficial approach to the problem—is widespread. In many cases, the practical application of this approach leads to no more than a mechanical solution of the problems. The handicapped child is placed in an ordinary class in a normal school, among normally developing contemporaries, and is given the opportunity to spend a small amount of extra time with a specialist in the education of persons with his kind of handicap. For all the apparent attractiveness of the slogan "integration in education", the superficial approach cannot be considered as a step forward in special education.

To make this clear, let us look at the concept, and the goals and problems, of integration.

First, since education in school represents only a small part of a person's life, and a period during which he is not independent, what is of greatest importance is his subsequent integration in society when he is independent. The completeness and success of this integration depend on how satisfactory the person's contacts and interaction turn out to be with those around him, at home and at work.

For a handicapped person, the chances of establishing sound relationships with other people and of becoming a successful worker are, in their turn, governed by the extent to which he has been prepared for such things by his education. This is a matter where it is helpful to begin a pre-school education at the earliest possible age, aimed at remedying the handicap, and where help is given by the whole system of organization and work in special schools, which takes account, for each particular kind of handicap, of the peculiarities of the child's mental and physical development and of his capabilities. In such a school, the child is one among equals. The system is designed to develop the personalities of handicapped children as comprehensively as possible.

When he is integrated into the ordinary education system, in the sense of being placed in a normal school among normally developing children, the handicapped child in effect finds himself in a situation of inequality, in far more difficult circumstances than the other children. Handicapped children are, as a rule, incapable of assimilating subject-matter or of completing exercises at the same rate as other children, and, in the circumstances we have described, they are deprived of the necessary educational facilities and are unable to obtain adequate training for employment.

In our opinion, the integration of handicapped children during the period of their education must, under an advanced system of special education, be understood first and foremost as the incorporation of special education into the ordinary education system. This in turn implies that the sum of knowledge, habits and skills which the handicapped children will be asked to acquire must correspond to a particular stage in the education of normally developing children. The mentally handicapped are an exception in this respect, since, because of their mental characteristics, there is a substantial part of the curriculum of a normal school which they are incapable of assimilating, even in specially created optimal circumstances.

The preparation of handicapped young people for integration into society can be undertaken best in special schools. This is so because, in a special school, the process of educating and bringing up the child is carried out *in its entirety* by specially trained professional teachers using special equipment and methods, at the speed and in the order which are appropriate for each category of handicap. Where necessary, the curricula of special schools are supplemented by additional material. The schools have special workshops with appropriate equipment and skilled instructors to prepare the children for employment. It is only within the framework of such schools that it is possible to organize specialized medical care, including the necessary systematic remedial work.

In the USSR (where education is compulsory for all children, including of course the handicapped, medical care is free, and special schools and pre-school institutions receive additional funds), experience of the development of the special education system, including testing of the feasibility of incorporating individual handicapped children and individual classes for such children into ordinary ("normal") schools, has confirmed that the most effective means of preparing handicapped children for their integration in society is to educate them in a special school.

This does not preclude the possibility of educating in normal schools individual handicapped children who, thanks to their abilities, to their level of development, and to the fact that they are equipped with special aids, are in a position to assimilate the lessons on an equal footing with their normally developing classmates. Given those conditions, handicapped young people (with the exception of the mentally handicapped) are capable of going on to the higher levels of the normal education system (specialized secondary schools and higher educational establishments) once they have completed their studies at the previous level in a special school equivalent to the corresponding stage in that system.

While a child is being educated in a special school, the necessary integration with normally developing children is ensured by means of extra-curricular activities (games, excursions, club meetings and

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Photo © Thomas Bergman, from *Fingers that See,* Liber publishers, Stockholm

various forms of amateur activity, etc.); during vocational training, integration is ensured through practical work in a general production unit.

Experience shows that, once they have acquired an adequate level of general education and vocational training in a special school, handicapped young people are capable of working successfully on their own. For example, the mentally handicapped prove capable, in approximately 50 per cent of cases, of working successfully in jobs for which they have received vocational training at school.

From an analysis of the problem, it can be said that genuine (as opposed to mechanical) integration of the handicapped into the general educational and social structure is possible, subject to certain conditions.

The first of those conditions is the elimination by legislation of all forms of discrimination that may exist against the handicapped in society (in the field of law, this concerns particularly the regulations governing access to employment). Due allowance must, of course, be made for the limitations which the handicap in question imposes. Thus, in the USSR secondary education for handicapped children is prolonged from two to four years. The majority of the schools are boarding schools, and the teaching and educational equipment are provided by the State.

The second is the acquisition by the handicapped (with the exception of the mentally handicapped) of a sound education (with no omissions) to a level no lower than the State-wide mandatory standard for normally developing young people. The Youth Employment Commission, which sits on all local government bodies in the USSR, is bound to set aside, as a matter of priority, jobs for young handicapped persons.

The third is vocational training which will give the handicapped the ability to work in industry today. Soviet specialized schools are equipped with professional workshops which provide handicapped young people with a training in various professions.

The fourth is the provision for the handicapped of supplementary social security benefits which will, for example, give them extra funds to meet certain needs associated with their handicap. The Soviet State spends from three to five times more on the education of a handicapped child in a special school than on a child in an ordinary school.

The fifth condition, obviously, is to educate normally developing children to have a proper attitude to people with handicaps. The fulfilment of these conditions gives handicapped young people the chance to pursue their studies at the higher level, and, when their studies are completed, to find employment in all the spheres of economic, cultural and scientific activity. ■

THE GIMBI SCHOOL FOR THE BLIND, ETHIOPIA

In the early 1970s, a group of Ethiopian church leaders, with the assistance of an organization for the blind of the Federal Republic of Germany, established a school for the blind at Gimbi, in eastern Ethiopia. The purpose of the school was to show that, far from needing charity or pity, the blind are fully capable of participating in all spheres of life. High priority is therefore given at Gimbi to preparing blind pupils for life in their communities, teaching them

how to handle social and everyday tasks and providing them with vocational training. Top photo, arithmetic is taught with the aid of special frames and Japanese abaci, a gift from abroad. Centre photo, two pupils examine the articles on the class "discovery board". Bottom photo, with the aid of a teacher, a pupil measures part of the school building using a rule with a slide made in the school workshops.

Photos Unesco. From a slide presentation of a Unesco project on "Innovative information and examples of good practice in education of the handicapped".

The rights of mental

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The Declaration on the Rights of Mentally Handicapped Persons, proclaimed by the United Nations General Assembly on 20 December 1971, marked an important step forward for the world's mentally handicapped. One of the documents on which the UN Declaration was based was a "Declaration of General and Special Rights of the Mentally Handicapped" which had been developed and adopted by the International League of Societies for the Mentally Handicapped (ILSMH). The League (now the International League of Societies for persons with Mental Handicap) is a Brussels-based non-governmental organization which was founded in 1960 to promote the interests of the mentally handicapped. Its membership is drawn from over 60 countries. A study carried out in co-operation with the League in 1974-1975 reached the conclusion that no country in the world had then implemented all the rights set forth in the UN Declaration for any of its

ARTICLE 1

The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.

- Is the mentally retarded child provided with the same right to life, including the same medical life-saving remedies at birth and later, as another child?
- Is the basic right to have a caring parent or parent surrogate, who provides both nurture and advocacy, supported to the same extent as for a normal child? Can a retarded child be adopted?
- Is the retarded child entitled to education for at least the same number of years as other children?
- Is the mentally retarded adult permitted to vote unless he or she has been specifically found ineligible under a general law specifying when the franchise may be denied?
- Is the retarded person given the same help and protection by the police as are other citizens?
- Is the retarded person advised of his rights and responsibilities as a citizen in ways which he can understand?
- Are the members of the police force oriented to understand the retarded person's behaviour?
- If charged with a crime, is the retarded person presumed innocent until proven otherwise? Is this presumption accepted by the general public and the police?
- Are groups of retarded persons or individuals often refused the use of public premises such as playgrounds, buses, restaurants, etc., simply on the grounds that they are "different" or perhaps disconcerting to other clientele?
- Is there any kind of "oversight agent" to assure that basic rights are enforced?

ARTICLE 2

The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.

- Is there a maternal and child health service which reaches all expectant mothers and their infants with prenatal care, well-baby care, and early intervention for infants who appear to be "at risk"?
- Is the medical care given to infants and children who are known to be handicapped of as high quality as is given to children believed to be "normal"?
- Is the same quality of dental care, immunization, routine screening for hearing and vision impairments, and the like, provided for retarded as well as for other children? Is this quality the same in the various clinics, group practices and special residential facilities?
- Do foster parents who care for retarded persons have access to medical care for them of the same quality as they would expect to secure for their own family members? Do foster children in fact receive equal care?
- Are retarded persons given doses of tranquilizing drugs in excess of those given to persons not considered retarded? Is this done for the convenience of the persons caring for them, to make them more docile?
- Can a mentally retarded person with an ordinary physical disorder or disease requiring hospitalization be admitted and receive the same quality of care, degree of attention to his comfort and wishes, and the same privileges of having visitors, etc, as other citizens having the same illness?
- Are the rights of the retarded person respected to the extent that he is encouraged to participate in decisions about his treatment to the full degree of his understanding? Are explanations of conditions and proposed treatments made to him in language he is most likely to understand? If he cannot participate, is his parent or guardian fully informed and consulted?
- If there are free public schools for normal children, are there also free school programmes especially suited to the needs of the retarded of the same ages which are sufficient in quantity, quality, geographical distribution and accessibility? If parents pay tuition for normal children, do they have to pay more for education of their retarded children? Are there provisions for even the most severely and profoundly retarded who live at home?
- Are the educational provisions for children in residential facilities at least as extensive and suitable as for those living in natural homes? And vice versa?
- Is the education programme oriented toward developing social independence (as far as possible) for the retarded person? Are there programmes leading to appropriate employment in economically valued jobs which actually exist in the economy of the country?
- Does the fact of having been in a special school or class cause discrimination in employment unrelated to the person's actual ability to do the job?
- Are there programmes for the proper preparation of teachers, therapists, counselors and physicians to meet the needs of the present and future services?

ARTICLE 3

The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.

- Are there barriers (laws, attitudes) which prevent a mentally retarded person from obtaining a job which he is capable of performing?
- Are there circumstances under which he may be paid less than another person for an equal amount of work?
- Are persons in residential facilities who work regularly at tasks which contribute to the running of the facility (janitorial work, kitchen work, etc, beyond what would be their share in their own homes) paid a fair wage for this work? Are they permitted to keep at least part of their earnings for their personal use (rather than paying it all toward the cost of food and shelter at the facility)?
- If a retarded adult is unable to earn at least as much as would be considered a "living wage" for another worker, is there a system (social insurance, compensation) which permits him to receive a regular income from public funds as a matter of right?
- Is the social insurance or assistance benefit sufficient, considering the additional costs of living which handicaps may impose?
- Are there family allowances or "invalidity" allowances paid to the parents (as well as foster parents) who maintain their child at home, to assist them in meeting the extra costs of caring for such a child, as compared to a normal child? Are similar allowances available for disabled adults?
- Is there a national health service or a national system of paying for health care such that the services of hospitals, clinics, physicians, etc. are either free or available at a cost no greater than a non-handicapped person would pay?
- Is there adequate insurance (or other alternative) against unemployment ? Does the mentally retarded worker have the same rights as other workers?
- If there are laws which require or favour the employment of handicapped persons, are the mentally retarded also covered by these provisions?
- If the retarded adult needs further training (vocational or other adult education) is it available to him on a basis at least comparable to other persons?

ARTICLE 4

Whenever possible the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.

- Do physicians, teachers and other professional persons who advise the family give the family encouragement to keep their child with them? Is practical help given to make this more feasible?
- Are parents and foster parents respected as the people who have the first responsibility for the care, nurture and education of their retarded child as for their normal child?
- Do professional people share their knowledge of the child's condition and potentials for growth with the parents or foster parents, and assist them to understand how to foster growth in accordance with such potentials?
- Are community recreation and leisure time facilities open to retarded persons? Is any effort made to provide adapted programmes (for example, special swimming lessons)? Are these facilities physically accessible (free of architectural barriers) to retarded persons with physical handicaps? Are the churches and religious organizations open and receptive to retarded persons? Are public attitudes accepting of people who are different?
- If residential care is provided other than in natural homes and foster family homes, are the facilities homelike? Are they situated in residential areas? Are the conditions of living such as to encourage the retarded residents to become as personally independent as possible, and to make choices for themselves in respect to activities, friends, articles of personal use, clothing, etc.? Does the individual have a choice among alternative arrangements? Does this include a choice to have a single room or to choose with whom he will share quarters? If he is unable to make a choice for himself, does his personal representative have an opportunity to do so?
- Do such facilities accommodate persons of both sexes? Are they convenient to local transportation? Do the conditions encourage the retarded residents to participate in community activities and to behave in as culturally normative a way as is compatible with the degree of handicap?
- Are residential facilities distributed in the various residential neighbourhoods so that there is not an excessive concentration in any one area and so that the residents have opportunity for informal interaction with neighbours and normal peer groups?
- Are the families of residents actively encouraged to visit frequently and informally the retarded member who is living away from home? Does he have something to say about when and how he visits them?
- Are steps taken to minimize expressions of prejudice or discrimination by neighbours toward retarded persons living or moving into apartments, hostels, etc. in the community?
- Are architectural barriers to persons with physical handicaps reduced to a minimum?
- Are there appropriate daytime activities outside the home for persons who are too handicapped to be employed for wages?

ARTICLE 5

The mentally retarded person has a right to a qualified guardian, when this is required, to protect his personal well-being and interests.

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mentally retarded citizens, nor** any **of the rights fully for all of its retarded citizens. Consequently, the League set up a task group to prepare materials which would help its member societies to initiate steps toward the implementation of these rights in their respective countries, the first step being to make a careful analysis of the extent to which the rights were currently observed in practice. On this double page, the* Unesco Courier *presents the text of the United Nations Declaration, accompanied by a series of searching questions drawn up by the League's task group. We hope that these questions will draw increased attention to the condition of mentally handicapped persons and will help readers to work out for themselves how well each major right is being applied in their country.

• Is there a formal procedure for determining whether a person is impaired in such a way as to require a guardian (limited or plenary) and does such procedure provide for (1) evidence to be presented both for and against the finding, (2) legal representation for the retarded person, (3) adequate professional evaluation of his specific capacities and deficits relative to his making appropriate decisions for himself in his own interest and according to his own preferences?

• Is the legal procedure to declare a mentally retarded person in need of guardianship, or the actual appointment of a guardian, as the case may be, costly, or are provisions made for these procedures to be carried out without cost to the person or his family?

• When a person identified as mentally retarded becomes of age, is he necessarily presumed to be incompetent? Is he so treated by parents and others without objective verification?

• What happens to a mentally retarded person when he is orphaned or has no family or is abandoned by his family? Are active interventions assured in this situation? Are there alternatives to admission to an institution?

• Are there available persons qualified to act as guardians of individuals when no appropriate relative or friend offers?

• Are there public or private agencies legally authorized to intervene on behalf of mentally retarded persons where their welfare is threatened?

• Do specific guardianship societies for the mentally retarded exist independent of agencies providing care and training? Are there programmes to assure the appointment of a guardian (limited or plenary) if needed?

• Are there other forms of public or private advocacy of retarded persons apart from or instead of, guardianship? Is there active recruitment of volunteers to act as guardians or as "citizen advocates"?

• Is there any public officer who acts as guardian either in an emergency or when no other is available?

• Are the directors of institutions or other persons who serve the retarded professionally considered ineligible to act also as guardians of their clients/patients?

• Are there legal provisions to assure that the person entrusted with the guardianship of a mentally retarded person does not neglect the person or mismanage his funds? Are there special follow-up programmes for mentally retarded people who have been found in need of guardianship?

• Is it possible to separate guardianship of the person and guardianship of property?

• Are there provisions for "limited guardianship", i.e. assignment of decision-making responsibilities to the guardian only to the extent necessary in the individual case?

• Is a seriously incapacitated person who has some residual capacity to make decisions allowed to take advantage of that capacity?

ARTICLE 6 (first part)

The mentally retarded person must be protected from every kind of exploitation, degrading treatment and abuse.

• Do the regular protective services for abandoned, neglected or orphaned children extend equally to retarded children?

• Do nurses, physicians and social workers show equal zeal in reporting cases of child neglect or abuse, or malnutrition, etc. for retarded children as for others? For those in institutions also?

• Are professional protective workers instructed to deal with the retarded and how to do it?

• Are mentally retarded children or adults exhibited or exposed to visitations by members of the public or by the press or professional workers under circumstances which would be considered inappropriate in a regular public school or hospital?

• Are retarded pupils given the least desirable classrooms in the school buildings, or usually expected to use buildings abandoned for use by normal people?

• Is "labeling" applied for purposes other than constructive diagnosis and prescriptive programming or scientific study?

• Are there places where the surroundings of the retarded persons are made visibly humiliating such as by the use of bars on windows or by requiring the retarded persons to be seen by strangers in inferior clothing, or not clothed?

• Are reporters or comedians rebuked when or if they use insulting language in referring to the mentally retarded, or if they make slurring jokes?

ARTICLE 6 (second part)

...If prosecuted for any offence, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.

• Is the mentally retarded person entitled to all the legal safeguards due to any other citizen accused of a crime?

• Is the person who is recognized as mentally retarded and who is unable to understand police and judicial procedures afforded proper assistance in the exercise of his rights?

• Do the police receive any training and guidance in the recognition and pre-trial handling of mentally retarded persons suspected of crime?

• Does the mentally retarded person have a right to the presence of a lawyer, relative, or friend during the course of any police interrogation? Does he (or his guardian or parent) have an opportunity to choose the person who will represent him?

• Does he have a right to the guiding hand of counsel (lawyer) at every stage of a criminal proceeding?

• In any prosecutorial proceedings, is a person believed to be mentally retarded entitled to a diagnosis and evaluation of his social capability by qualified experts?

• Does that evaluation include a determination as to whether he is "fit to stand trial" (i.e. mentally competent to understand proceedings and assist his counsel in his defence)?

• If found not fit to stand trial, is the retarded person entitled to a reasonably prompt opportunity to have a trial or to have the charges against him withdrawn?

• If the retarded person (charged with crime but found not fit to stand trial) is diverted to civil authorities on grounds of his alleged dangerousness, is he entitled to proper legal safeguards to the same extent as any other alleged "dangerous" person not accused or convicted of any crime?

• At a criminal trial, is the mentally retarded person entitled to the defence of "diminished mental responsibility" or similar defence to mitigate or excuse from punishment in such cases in which the person lacked the mental capacity to form a criminal purpose, or had some such degree of incapacity?

• If convicted of a crime, or if otherwise placed in custody, is the mentally retarded person entitled to receive treatment in the least restrictive setting suited to his needs, his degree of responsibility and the public's safety?

• If placed under custody (except for a specified short period of time), is he entitled to an automatic periodic review and a right of appeal to independent, higher authorities?

ARTICLE 7

Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and the right of appeal to higher authorities.

• Before any procedures to deny or restrict rights are initiated, are other less restrictive or non-restrictive procedures fully considered, such as those which provide him with counseling, advice, or social and emotional support for his own decision-making and action?

• Before any restriction is considered, is an evaluation made of his social capabilities as related specifically to his ability to exercise the right in question having in mind that many citizens are expected to make decisions for themselves which do entail risk and which may not always have the most desirable results? If rights are to be restricted, is the determination of need for such restriction preceded by a careful evaluation of the retarded person's specific capabilities which is carried out by experts in the evaluation of social competence in persons who are mentally retarded? Is the expert evaluation interdisciplinary?

• When a person is found incapable of exercising certain rights, is this finding based on essential protection, i.e. is the restriction necessary to protect the individual himself or others from significant harm?

• Is any restriction which is imposed limited only to the specific activities (i.e. exercise of specific rights) in respect to which the person has been found incapacitated, leaving to him those rights he may prudently be allowed to exercise?

• If some restriction is so required, is the restriction carried out in a way which imposes the minimum degree of constraint needed to accomplish its purpose? (i.e. limited guardianship rather than plenary guardianship; supervision rather than committment, community based rather than institutional care, if possible, etc.)

• Does the retarded person, his family, or other interested person receive prior notice in advance of any serious restrictive proceedings?

• Is the person, his family, or his friends entitled to the assistance of advocates to act on behalf of the mentally retarded person in any proceedings?

• Does the retarded person have access to a qualified representative (attorney, advocate) whose interests do not conflict with his own?

• Are the opportunities to ask for reconsideration or independent review of any restriction, both at the time imposed and later, appropriate to the degree and duration of the restriction? Is there also automatic periodic review?

• If the rights involved are fundamental ones, are the proceedings judicial in character?

• Does the mentally retarded person or his representative have opportunities of submitting information to the tribunal, appearing before it, and challenging information submitted by others?

• Is the retarded person or his representative informed of his right to appeal and given assistance, legal and otherwise, in exercising that right?

• Does the retarded person (or his natural advocate, e.g. relative, general guardian) have a right to select the attorney or other persons who may represent him in such proceedings?

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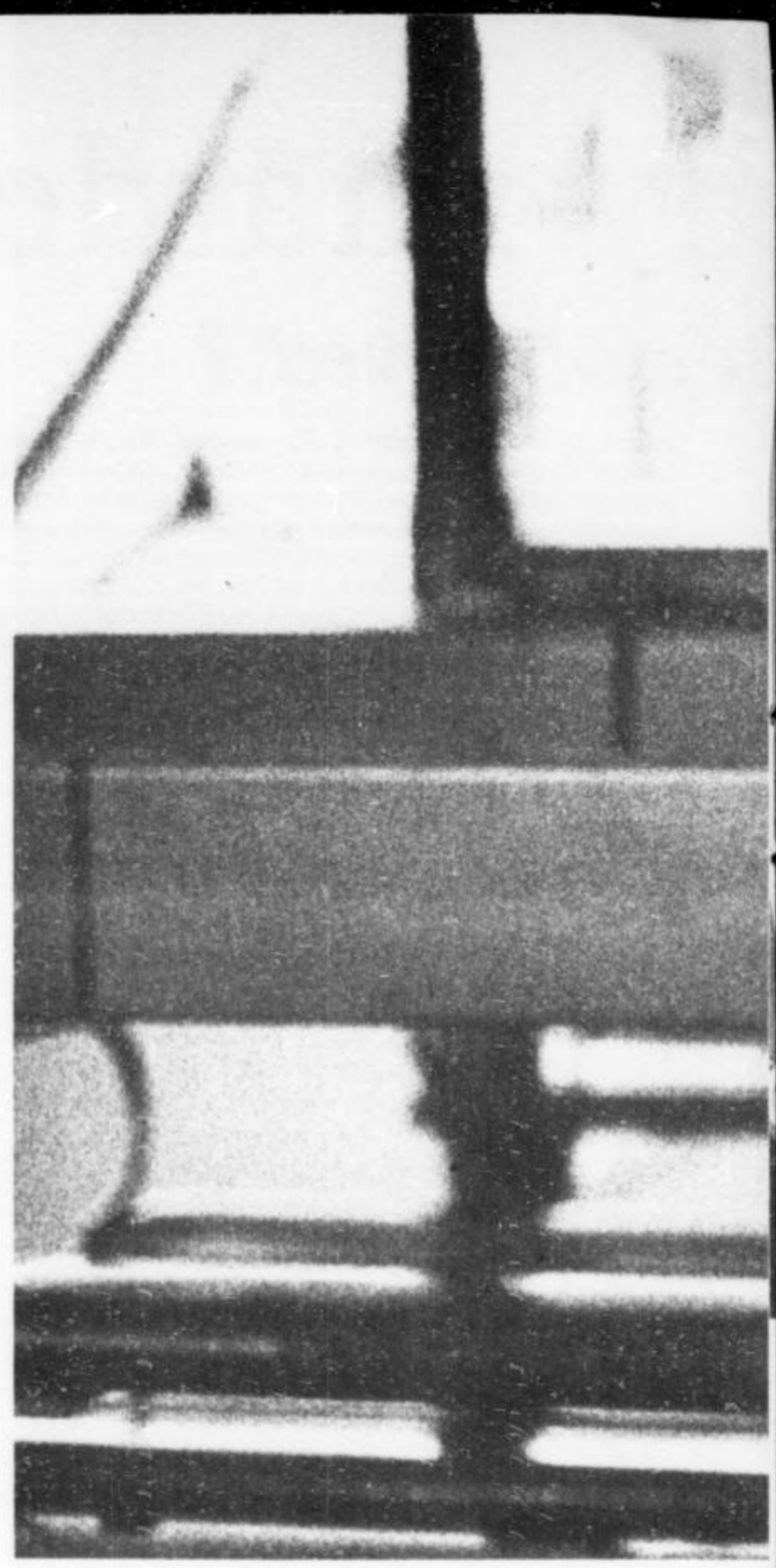
Special schools or integrated education?

II. 'Our task is to bring the retarded into the community from which they have been excluded'



by Marten Söder

AT the end of the 1960s, normalization and integration became widely accepted watchwords for those concerned with the welfare of mentally handicapped children. According to this new approach, the mentally retarded were to enjoy the same conditions as other children, living with them and attending their schools. This outlook was largely a reaction to the formerly prevalent view which had resulted in the segregation of mentally retarded youngsters in special schools and institutions.

The integrationist viewpoint contrasts sharply with its predecessor not only on the measures to be undertaken on behalf of the handicapped but on other important points, such as the definition of what constitutes a handicap. According to the segregationist thesis, mental retardation is an absolute, unalterable defect and nothing can be done about it. Mentally retarded people are defective and the appropriate action is to separate them from the rest of society. Segregation is in any case part of the natural order of things.

The integrationist position, on the other hand, stresses that handicaps are relative, in the sense that they only exist in relation to a given environment. This approach is coupled with a more dynamic, optimistic belief in the potential of mentally handicapped people than the static pessimism of the segregationist view. It holds that integration is the "natural" condition, and that segregation is caused by social and political decisions to separate the handicapped from the non-handicapped. Such decisions attach a label to the handicapped which stigmatizes them and limits their possibilities of living a "normal" life.

Since segregation is created by social and political decisions, so the integrationist argument continues, then integration can be brought about when the authorities take measures which separate the handicapped as little as possible from the non-handicapped. In schools one might imagine a kind of sliding scale of integration whereby a handicapped child in an ordinary class is "more integrated" than he or she would be in a special class, while a special class forming part of an ordinary school is "more integrated" than a special school.

In Sweden, integration of the mentally handicapped has taken the form of "facility integration", whereby special schools have been assigned classrooms in ordinary school buildings, as opposed to "individual integration" whereby individual handicapped pupils are taught in ordinary classes. During the 1970s, facility integration took place at a rapid rate, and today over 90 per cent of Sweden's special school classes are integrated on ordinary school premises.

Before examining how successful this approach has been, let us first examine the idea of integration and its implications, especially as they appear in the Swedish context.

Many writers who have studied the question have made a sharp distinction between a superficial, "organized" form of mixing handicapped and non-handicapped persons and a more genuine and psychologically meaningful integration which they often refer to as "social integration". The latter assumes that social relations will be established between the two groups, and some writers also stress how important it is in this respect that handicapped persons should feel a sense of security in their relations with others.

This distinction calls into question a fundamental assumption of the integrationist position, the belief that handicapped persons are segregated from the rest of the community primarily by the special educational measures taken on their behalf. But surely this ignores the possibility that segregationist mechanisms may also exist in the "normal" environments in which the handicapped person may be placed. Here the integrationist viewpoint runs the risk of romanticizing the real world by regarding it as a welcoming community in which deviants are automatically accepted in a "normal" context when decisions are taken to place them there. In the desire to abolish segregative measures taken by the authorities, the segregative measures of the real world may be overlooked.

This leads to another point on which the integrationist position is vulnerable to criticism. This is its assumption that the in-

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Photo © Thomas Bergman, from *Who Understands Us?,* Liber publishers, Stockholm

tegration of mentally retarded children in school is somehow synonymous with what sociologists call their "societal integration", their full integration into society as adults—or at any rate that there is no inconsistency between these two processes. But school, it might be argued, is not the same as society. Integration into the school, therefore, cannot be the same as integration into society. In response to this it is often said that integration into school constitutes *a means to the end* of societal integration.

One way of testing whether this is so in practice is to examine the avowed aims of schools regarding their mentally retarded pupils. In the case of Sweden the results of such an enquiry are illuminating. According to Swedish law, special schools for handicapped children aim to "promote the development of the pupils into harmonious people and into competent and responsible adults." In this respect there is no divergence between the aims of the special school and those of the ordinary comprehensive school. However, other texts relating to the curricula in the two types of school tell a different story.

In the special school, the teacher is to "endeavour to promote [the pupil's] personal development", whereas in the comprehensive school the aim is to "endeavour to promote his personal maturity into a free, independent and harmonious person." Whereas the special school sets out to "develop all aspects of the pupil, encourage alertness, provide motivation for study and work and promote emotional balance", the pupils at the comprehensive school are to "prepare themselves for their roles as active citizens in the society of tomorrow." In the special school, each pupil is to be brought to "develop his various qualities and come to terms with personal problems", whereas his peers at the comprehensive school are "in the long term to be a positively creative power in the development of society."

This comparison between the aims of ordinary comprehensive school education and those of special school education makes it clear that in Sweden at any rate the aims of the special school centre more on the individual than those of the ordinary school. The special school sets out to produce well-adjusted and "harmonious" mentally retarded adults who are able to cope with their personal problems. The ordinary school sets out to produce active, productive and critical citizens who are capable of full participation in society. Given this disparity of aims, it is hard to see how integrating special schools into the ordinary education system can lead necessarily to societal integration.

Another problem arising from the integrationist approach is its emphasis on social goals at the expense of educational ones. For although special education may not aim at the societal integration of the handicapped, this does not mean that it has no aims as regards the pupil's adult life. In order to "promote the development of the pupils into harmonious people and competent and responsible adults", special demands are made in the special school, such as "the need to gear teaching to the individual level and special characteristics of each pupil in various areas of learning and training". The special measures required consist of creating smaller groups for tuition and providing more resources than are usual in the ordinary school system.

But these demands for specially arranged learning situations always produce segregation in some form or other. And so if we are seeking to promote social integration, these educational demands must be questioned. Here there is an obvious conflict between the aims of social integration and the educational demands ensuing from the need to produce "competent and responsible adults". The integrationist view often obscures this conflict of aims.

The conflict between educational and social goals has not yet become acute in Sweden, because integration has taken the form of facility integration. This is one of the conclusions which may be drawn from a large-scale project to evaluate the integration of special schools for the handicapped into the ordinary school system which was recently carried out by the department of sociology at the University of Uppsala. A number of different concepts, each describing a different kind of integration, were formulated as a starting point for our studies. We differentiated between four forms of integration: physical, functional, social and societal.

By *physical integration* we mean the reduction of the physical distance between the mentally retarded and the non-retarded.

By *functional integration* we mean the reduction of the functional distance between the two groups when they use dif-

ferent equipment and resources. Functional integration is therefore a question of the joint utilization of resources.

Social integration entails a reduction in the social distance between the two groups. Social distance implies both lack of contact and the psychological feeling of being cut off. The mentally retarded are socially integrated if they form part of a community with non-retarded persons, come into regular and spontaneous contact with them, and feel themselves to be a natural part of the group.

Societal integration refers to adults, as indicated above, and signifies that the mentally retarded have, as adults, the same access to resources as others, the same opportunity to influence their own situation, have a productive working role, and form part of a social community with others.

By using these terms we were able to describe various aspects of integration in terms of physical distances and of the extent to which resources were jointly used by both handicapped and non-handicapped. This conceptual framework also enabled us to bring into focus the problems involved in relating physical and functional integration on the one hand, and social and societal integration on the other. And this, as shown by the above critique of the integrationist view, is a matter of particular urgency.

In Sweden, facility integration has first and foremost taken the form of physical integration. To some extent it has also involved the special school and the ordinary school making use of joint resources. Facility integration has thus been associated with a degree of functional integration.

Any more advanced form of functional integraiton in the shape of co-operation at the teaching level has, however, been a relatively rare occurrence. With respect to social integration, in general it can be said that this has not taken place.

Thus one of the big question marks concerning the integration of special schools in Sweden is why so little co-operation and social contact has developed from the "base" formed by facility integration. For such co-operation is usually sporadic, consisting of joint activities of an exceptional nature.

Nevertheless, school staff were consistently favourably disposed towards full-scale co-operation between the two types of school. From a study of fifty integrated schools, it emerged that approximately 80 per cent of teachers in both the ordinary and the special school were in favour of co-operation in one of the practical subjects. Even though there may be a difference between expressing a favourable attitude on a questionnaire and accepting the consequences in practice, it would seem to be a simplification to blame the low occurrence of co-operation on lack of interest on the part of the teachers.

Perhaps one reason why there has not been more co-operation is that co-operation has been regarded only as a subsidiary goal of integration. Instead, the emphasis has been laid on promoting physical integration and the co-ordination of certain resources. There has been surprisingly little discussion of how facility integration affects the actual educational work within the special school.

It is difficult to make any general assessments about social integration in the facility-integrated school. But if we were to attempt to characterize the social relations between special school and ordinary school pupils, they might best be described as "accepting indifference". The mentally retarded pupils were, as a rule, accepted by their peers in the ordinary school. There was virtually never any systematic harassment or bullying. But more positive relations were also uncommon. Facility integration has not resulted in any actual social integration.

However, the "normal" school environment is in itself poorly suited to social integration of the mentally retarded. Social contact between pupils is largely along class lines, and contact between school classes at different levels is uncommon. The lack of integration of mentally retarded pupils must be seen in this light.

Another factor which renders social integration more difficult is that the special schools have such large catchment areas. "Normal" children attend the same school as their friends at home, at least at the primary and middle levels. By and large the same children mix together at school and in their leisure time at home. Mentally retarded pupils often have long journeys to school. The non-retarded friends they have at home go to other schools, and their friends at school live near the school. This is a fact which also makes it more difficult for mentally retarded pupils in the same class to meet during their leisure time.

The conflict between educational and social goals really comes to a head, however, where individual integration is involved—when the mentally retarded pupils go into ordinary classes. This is generally regarded as the most far-reaching form of integration. Although the underlying assumption is that putting a handicapped child in an ordinary class automatically leads to him or her becoming "socially integrated", in a sense integration of this type also means that the mentally retarded pupil is confronted with the segregative mechanisms existing in the class.

At the same time, when individual integration is pursued, the conflict between the possible gains that might be made in social relations and the educational demands made by the curriculum becomes manifest. The "normal" school environment articulates and puts a premium on those very intellectual achievements which the mental disability of the retarded pupil does not allow him to produce. As in the case of social segregation, it is the "normal" school environment which operates in a segregative manner.

Dictionary definitions of the term *integration* tell us that it means uniting separate parts in a whole. According to the integrationist view, the detachment of the mentally retarded as a "separate part" arises as a result of social and political decisions and the special educational measures which are taken by the authorities. Our task, uniting the parts into a whole, consists in bringing the retarded into the community from which they have been excluded. But this view disregards the fact that segregation takes place in our society and in our schools irrespective of such official action: the educational and social measures of segregation are a part of the reality of the "normal" school. The problems in what we have called the integrationist view arise from a refusal to accept that this is the case.

Marten Söder

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3 Photos Unesco. From a slide presentation of a Unesco project on "Innovative information and examples of good practice in education of the handicapped".

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1 Francesco (standing beside blackboard) is a victim of Down's Syndrome and suffers from mental retardation and serious visual and speech impairment. He is one of the 70,000 Italian handicapped pupils who attend ordinary schools. He is 12 years old and attends a first grade class in a lower secondary school. A pupil seated at the teacher's desk is explaining to the class the work he has done on the blackboard. When Francesco starts to interrupt him a girl goes up to Francesco and persuades him to go back to his place. She does this by touching him and showing acceptance and affection. The teacher, who is sitting at the back of the class, does not intervene.

2 Francesco also participates in manual activities. Here he is seen holding a cardboard box steady while a classmate cuts it out. They are making cylinders of different sizes for a geometry lesson.

3 Realizing that he is unable to follow the outline of a drawing correctly, Francesco asks a classmate to help him. He takes the girl's finger, puts it on his paper and says: "You are the train and I am the bicycle that runs after the train. "The girl traces the outline of the drawing with her finger while Francesco follows her finger with his pencil.

4 Using a mattress, Francesco has built himself a "hut" to which he withdraws when he wants to be alone. He goes to the hut to read while the rest of the class continues with the lesson.

Living and learning together

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Photos © Martin Knutsson, Munkhatteskolan, Malmö

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5 Just over three years ago the primary and secondary schools at Munkhätteskolan, near Malmö, Sweden, began to integrate handicapped pupils into their ordinary classes. They now have a total of twenty handicapped children, with two or three in each class. Specially adapted vehicles transport the handicapped pupils to and from school. Some pupils have up to an hour's journey in each direction.

6 Although some modifications have been made to the school buildings to enable handicapped pupils to get around more easily, it has not been necessary to make any major alterations to the classrooms. The disabled pupils are, however, provided with desks adapted to their special needs and, where necessary, with aids such as electric typewriters and reading lamps equipped with magnifying glasses.

7 From the start, the handicapped pupils were very well received by their classmates and relations between them have remained extremely good, both in the classroom and during leisure periods when they can often be seen playing together.

8 A gymnastics department has been created at Munkhätteskolan to enable the handicapped pupils to follow courses prescribed for them by specialists. They also take part in the ordinary physical training classes even if they cannot participate in all the exercises.

Communities that care

by Mahfoud Boucebci

Photo © Sylvia Quijano Gonzalez, Minusval, Madrid

SPECIAL education is not, whatever the term may suggest to the contrary, a distinct, separate form of education designed to produce social "outsiders". Nor is it a single, monolithic activity, for the notion of "mental handicap" covers a wide variety of conditions.

Special education must give permanent consideration to the place of the mentally handicapped in society today and tomorrow. When choosing an educational system for the handicapped, preference should be given to the one which is least likely to relegate them to a social backwater. As it happens, this type of system is best suited to the conditions and resources of the developing countries.

Furthermore, it would be very dangerous to establish a system of special education that excludes the family, for unless the family is made fully aware of the problems and allowed to participate in the care and training process, the disabled will rapidly become a marginal group completely alienated from and rejected by the community.

On the basis of these principles, various models of special education may be drawn up for the different age-groups. For very young children, the largest and most neglected group in the Third World, any break with traditional ways of stimulating and caring for infants must be avoided. The fact that specialists are available should not cut the child off from its mother or family.

Educators working with disabled children must thus be thoroughly familiar with the most widely used traditional methods of child care, as well as the place of the handicapped in the traditional culture. The first risk to be parried is that when an infant is found to be handicapped it will be rejected by its family.

Motor-sensory stimulation sessions in which several mothers and children take part have proved a practical and useful method, for they develop a relationship based directly on traditional community relations which is a source of encouragement and mutual assistance.

Two lines of approach have been developed in work with young handicapped children in the Algiers area.

The first involves groups of children of the same size or at the same level of intellectual development. Initially, children with serious human relations problems or those deprived of autonomy of movement are excluded from these groups. But as a general rule every effort is made to provide care and training for disabled children in nursery schools for "normal" children.

Information campaigns have helped to make the staff of these institutions aware of the plight of handicapped children, and it has been possible to place them alongside normal children. We have been able to do this with certain children suffering from Down's syndrome, certain deaf children, children suffering from motor cerebral deficiency, epileptic children whose fits have been brought under control, and epileptics with or without slight mental deficiency or a motor-neurological deficiency.

Placing these children in a "normal" environment was not easy in the early days. There were very few nursery schools and requests for admission were many. At the same time, failure to recognize the problems raised by handicaps, as well as false ideas and prejudices reinforced the often negative ideas of some of the teachers. However, information sessions organized during the pre-school teachers' training courses helped to make the staff aware of these problems and to dedramatize the situation.

But the fact remains that the admission of disabled children to ordinary nursery schools is only successful with certain categories of disability, for there is always a risk that disabled children will be left out of things. If they are too abnormal or raise too many problems they will be rejected, with traumatic consequences both for them and for their families.

For the other categories of pre-school children we have adopted a second approach in the form of experimental "district centres". These centres do not have elaborate facilities, they are near the children's homes, and they call for participation on the part of the parents. The key to this type of education is continuity as the child grows older, either in the same institution or in another school where the basic principles of the district centre continue to be applied.

The parents must be involved in educating their child, and there must be an incentive for them to join in the activities of the various associations and societies for the handicapped. Where these possibilities do not exist, parents should be kept informed of the many ways in which they can help their child, for paradoxically such opportunities are often neglected. The family can be told what progress to expect in the short, medium and long term, and informed about the possible advantages of certain types of specialized training, or about whether medication is required. One vital point that needs to be stressed to the parents is that progress may take time, perhaps even a very long time.

Finally, we believe that some types of handicap should always be accommodated within the normal educational system—for example, a class for blind children in an ordinary school.

The role of institutions such as district centres is decisive for young children and adolescents who are "not capable of benefiting from a scholastic education". These children can only be treated if the family and community are prepared to accept the handicap and recognize that it is impossible for them to attend school. The day centres, with relatively small premises and simple but functional equipment, can each accommodate between thirty and forty local children aged four to thirteen. Children with multiple handicaps are admitted provided that they are affected with minor motor or sensory handicaps connected with mental deficiency. Bedridden children and those with serious personality disorders are not accepted. Each centre has between eight and twelve teachers.

The centres do not aim to provide an academic type of education. Their activities are directed towards *educating the child in the broadest sense*, and all their activities are in some way educative. They include:

- training for daily life, such as washing and dressing oneself; household chores such as laundry, cooking or gardening;

- activities designed to promote better knowledge of the environment including the discovery of nature: walks in the district, visits to the local market, to a public garden, a festival or cultural event, a swimming pool, pony club, the beach and the mountains. Through experiences like these the child is helped to make progress and acquires greater independence and ease in social relationships;

- educational games, weaving, carpentry, sewing and odd jobs about the house which are designed to develop sensory and manual skills;

- self-expression activities such as playing with water, sand, clay, paints and puppets, as well as music (singing and playing instruments) and psycho-motor activities;

- the rest of the child's life at the centre —breaks, meals, rest periods, etc.

This broad range of activities gradually leads to improvements in the child's speech, in the level of his practical and motor-sensory intelligence, and the integration of his bodily functions, and helps to develop his capacity for observation and expression so that he can participate more actively in the life of the community.

Pre-school and school activities that require abstract thought are only introduced for children who possess this capacity. The methods used are always based on concrete experience and take account of each child's individual learning rhythms and capabilities as well as his staying power.

Each pupil's progress is recorded in detail on special attainment and observation cards. This enables the teacher to pinpoint each child's specific problems and needs and to adjust his tuition accordingly.

The parents have an opportunity to meet the educational team every morning and evening and are often in contact with the psychologists. Regular parents' meetings are also organized, and as members of the parents' association the parents are encouraged to play an active role.

The atmosphere in the centres is generally very relaxed. Children, teachers and other staff members form one big family within which the child can develop in a secure environment and gradually become capable of more sustained effort. The centre may offer advantages over the home environment—in particular nourishing meals provided free—which help to promote the child's overall development.

Whatever the stage at which responsibility is assumed for a child, the objective is that he should be integrated into the community. And so, to avoid any break in the training process, vocational training centres and workshops should be planned right from the start.

The social situation in the developing countries and the vast number of children and young people in relation to the population as a whole make it imperative to provide care and training for these age groups.

But the structures outlined here and the approaches on which they are based should not be exclusive: other approaches should also be fostered. Craft work seems to be one of the most promising types of activity —with its possibilities for developing human relations—open to certain categories of the mentally handicapped.

The handicapped are still excluded from many cultural and leisure activities, especially in sport, where much remains to be done to make people aware of the needs of the handicapped. Swimming, for example, is one of the most beneficial activities for some handicapped persons, but paradoxically a handicap often rules out admittance to swimming pools.

Generally speaking, the independent African States have retained the main bulk of earlier legislation concerning the handicapped, and this is now outmoded. If jurists and sociologists could collaborate with educators and medical and health officials in the study of these problems, then it would be possible to review existing legislation and make further provisions for prevention, care and treatment of the mentally handicapped and the furtherance of their rights to special education and to their rightful place in the community. ■

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Sounds from silence
China's deaf children find a voice

by Li Hongtai and Shen Jiayin

IN old China the severely deaf, who cannot hear spoken language and thus fail to develop the power of speech, were subjected to widespread discrimination and deprived of the chance to be educated.

Today attitudes have totally changed. Education is provided for the deaf in schools whose target is to help their students to achieve all-round development.

Methods also have evolved. In the old days most teaching was done by means of gestures and facial expressions. This hindered the development of the students' ability to handle language and express their ideas.

To improve the education of the deaf, the Ministry of Education of the Central People's Government decided in 1954 to launch pilot speech teaching projects in certain schools for the deaf in order to develop the pupils' oral ability. Two years later, it was decided to start oral teaching in all schools for the deaf throughout the country.

The basis of this speech teaching is the Chinese Phonetic Alphabet. This alphabet has a comparatively small number of letters and is worked out in accordance with the phonemes, or speech sounds, of *putonghua,* the common speech of the Chinese language. It makes it easy for deaf children to learn pronunciation. The teaching materials used combine the study of transliteration with recognition of characters and words. The children learn to recognize characters and words and study the language on the basis of the learning of pronunciation. This approach overcomes the obstacles caused by the fact that the same Chinese character can represent a number of different sounds.

Whenever a new letter is introduced in the textbook, it is illustrated with diagrams and pictures of lip-rounding. The teacher demonstrates the position of the tongue and the lip movements while the pupils use mirrors to watch and imitate. Some letters are aspirated, some are not. The pupil is made to feel the difference by placing the back of his or her hand in front of the mouth to feel for the air flow. Some sounds are made with the vocal cords vibrating, others are not. The pupil learns to distinguish between them by touching the teacher's throat or his own. In a word, the pupil's senses of sight and touch, as well as his sixth sense, are brought fully into play to help him or her to grasp the correct way to articulate each letter.

The thinking of deaf children is necessarily linked to visual images and acts. It is thus essential that the teachers demonstrate real objects and use their histrionic gifts to the utmost. It is equally important that the meaning of the words should not be misunderstood. In the case of words or phrases that are difficult to define clearly, pupils are encouraged to apply them to real-life situations.

It is mainly through lip-reading that the pupils learn new things. However, this does not work with certain sounds such as *ge, ke,* and *he.* It is hard to distinguish between these sounds unless lip-reading is backed up by other means. So far the major tool used for this is the hand alphabet formulated in accordance with the Chinese Phonetic Alphabet. This alphabet is part of the syllabus in schools for the deaf because it can be used to express all the syllables in the Chinese language. By looking at the diagram, forming the hand alphabet with his fingers, and uttering the sound with his oral cavity, the pupil is using three sense-organs at a time. This imprints what he is learning more firmly on his memory and also helps to reinforce his grasp of ways of articulation.

Photo © The National Commission to Unesco of the People's Republic of China

Nevertheless, this hand alphabet has certain drawbacks when it is used to spell out a syllable which is usually made up of three phonemes. This means making a large number of finger movements, which might be acceptable when spelling out words, but not when it comes to sentences. Accordingly, some teachers began to think of the possibility of using a manual alphabet to spell out syllables instead of single phonemes. In collaboration with specialists from the Chinese Written Language Reform Research Institute, we have designed a system for finger-spelling syllables one at a time in which both hands are used (see diagram this page).

A pilot programme using these "manual syllables" is being carried out in a small number of schools, and the preliminary results suggest that they are easy to use. The changes in lip and finger movements are closely co-ordinated, and sign language thus becomes more simple, expressive and vivid in supplementing speech.

Thus the approach to speech training for deaf pupils which we are now beginning to systematize is based on oral teaching. Other forms of expressing language are used in support, and training in the use of the written language is reinforced.

■ **Li Hongtai and Shen Jiayin**

LI HONGTAI, *of China, is dean of Peking's No.1 school for the deaf. He helped to produce the first set of Chinese textbooks for the deaf, and is a correspondent with two periodicals for the deaf,* The Deaf in China *and* Newsletters for the Education of the Deaf.

SHEN JIAYIN, *of China, teaches at Peking's No. 4 school for the deaf, and was formerly on the staff of the Shanghai school for blind children. She is also concerned in the editing of textbooks used in schools for the blind, deaf and dumb, and a correspondent with* The Deaf in China *and* Newsletters for the Education of the Deaf.

Photos Liu Quanju © The National Commission to Unesco of the People's Republic of China

Eloquent hands enable a deaf Chinese youth to bring a smile to the face of his deaf companion. In China manual systems of communication (opposite page) are used in support of oral teaching for the deaf, to help them overcome their additional handicap of speech difficulties.

Blind workers assembling books in Braille in an Indian publishing house.

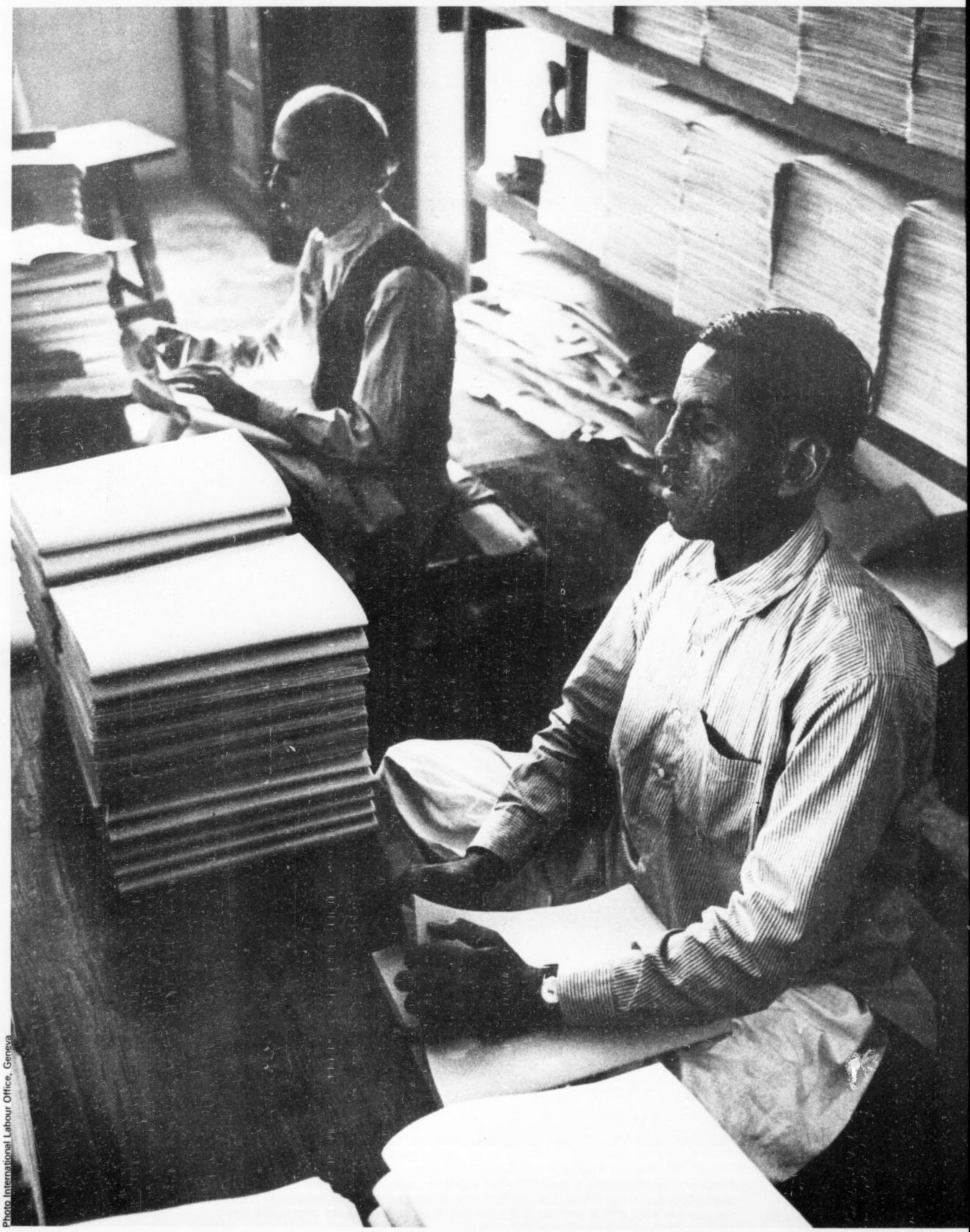

Photo International Labour Office, Geneva

Self-reliance and the right to work

by Ed. Sackstein

A major purpose of the 1981 International Year of Disabled Persons is to turn the spotlight on the handicapped and help remove the prejudice and discrimination which bar their way to "full participation and equality"—the UN theme for the Year.

In most situations, these two goals cannot be achieved unless the disabled get the opportunity to become self-supporting and to participate in active economic life.

It means training and jobs. This, of course, is easier said than done, for the alarming fact is that despite all efforts and appeals for aid, the outlook for handicapped people is as bleak as ever.

The majority of the world's disabled—300 million—live in developing countries which also have a backlog of over 300 million jobless or underemployed citizens.

To contemplate the possibility of placing many disabled in the open labour market is for most, therefore, just a pipe dream.

Consequently, the International Labour Organisation's main efforts have been directed towards the setting up of production workshops on small-scale industry lines, small business co-operatives and self-employment schemes for Third World disabled.

Nine in every ten of these people live in isolated rural communities and, for them, the ILO's efforts are directed to teaching practical skills for everyday life rather than a specific trade for which there may be little demand, if any.

In the industrialized countries, the current economic slump has thrown some 17 million people out of work, but no group is having a tougher time in the tight job market than disabled men and women who often are the first fired and last hired.

ED. SACKSTEIN, *of the United States of America, is deputy chief of the Vocational Rehabilitation Branch of the International Labour Organisation, Geneva. A specialist in vocational rehabilitation training and psychotherapy, he has special responsibility for developing vocational rehabilitation programmes for the mentally ill and for drug-dependent persons as well as for work on the prevention of alcoholism and drug addiction at the workplace.*

In some places, their rate of unemployment is twice that of able-bodied persons. Because of sex bias, the situation is doubly difficult for disabled females.

Experience has shown that protective legislation which aims at promoting employment of disabled people can help but that it is no panacea. In the United Kingdom, for example, the quota system has proved to be relatively ineffective in a depressed labour market situation.

Designated employment and reserved jobs programmes, even if implemented, provide little relief. Moreover, the jobs in question are usually menial, low-paid and of low status.

ILO specialists say that legislation concerning employment of the disabled would have a better chance to be effective if, instead of being coercive, it were more flexible and formulated in such a way as to stimulate private and government initiative.

Some countries pay grants and allowances to employers who offer training to disabled persons at the workplace. This is a positive development which should be encouraged further, together with financial incentives to make ergonomic and other job adaptations that facilitate and increase the performance of disabled workers.

In Sweden, the so-called "adjustment groups", sponsored jointly by management and labour, are helping in many enterprises to secure alternative employment for disabled people. Similar programmes are underway in Poland and Norway.

In other forms of vocational rehabilitation training, it is essential that the skills being taught are geared not only to the present-day needs of the labour market but also to future requirements resulting from technological and structural change.

Furthermore, vocational rehabilitation specialists must increasingly and directly plug in to the world of work if they wish to meet the challenge of preparing disabled persons in appropriate and realistic ways. It might be necessary for rehabilitation professionals to shed some of their traditionally "humanitarian" approach in favour of one which is tempered by the hard realities of the market place. The disabled are showing professionals and the non-disabled every day that they have enormous energy and potential to accomplish far more than was at one time thought possible. They therefore deserve and have the right to more opportunities to realize that potential.

There is also a certain danger in over-reliance on professionals. Over recent years vocational rehabilitation specialists have developed their field of work into a highly specialized discipline and the extensive research they have undertaken has yielded positive and often exciting results. This has, however, had the unfortunate consequence that the disabled, their families and the general public have come to believe that only the specialists can find solutions to their social and employment problems

When helping people with disabilities, or any group in a community with particular difficulties for that matter, higher priority should be given to encouraging each community to take on part of the challenge itself and to come up with simple workable solutions. This means contacting employers' groups, trade unions, employment exchanges, vocational schools, the press and private groups (such as, for example, concerned parents or citizens who have a direct interest in the problem). But let us by no means forget to include the direct participation of the disabled themselves in planning and implementing programmes on their own behalf.

In this context the new concept of vocational training developed by the ILO, and known as "Modules of Employable Skills", holds great promise of improved employment opportunity for the disabled.

The key to this system and its unique feature is creating completely self-contained training packages—or modular units—around each useful function and limited to the essential skills, knowledge and aptitudes required to perform a task. The relevance of this infinitely variable and flexible approach to training and employment of the disabled is obvious; for it allows the training and reintegration of those severely handicapped who can only undertake a limited range of activities.

An important objective of all ILO vocational rehabilitation projects in developing

countries is to try and ensure that they become self-sufficient and that they are profit-oriented right from the start.

An ILO expert, Edward Johnson, who has wide experience with rehabilitation programmes in the Third World, states that one purpose of rehabilitating a disabled person is to make a taxpayer out of him.

"This helps to convince governments, although that is not the main reason", he explains. "The object is to turn the disabled person into a self-reliant citizen, standing shoulder to shoulder with the able-bodied members of the community. Nothing gives disabled men and women the confidence they need as does the knowledge that they are doing a job of work, paying their taxes..."

Rehabilitation of the disabled does pay off in hard cash terms. For example, US Department of Labor statistics show that for every $1,000 invested in the rehabilitation of a disabled person $35,000 will be generated by that person's work during his lifetime, part of which goes to Federal and State taxes. Even more impressive, it is estimated that the employment of 100,000 disabled persons in the US adds at least $500 million to the GNP. And disabled persons who are economically independent do not burden community public assistance funds.

If present trends continue, and unless resolute remedial action is taken, the number of handicapped people seeking help might swell to some 800 million by the turn of the century. Among them will be an increasing number of people whose disability is an extreme difficulty in adjusting to existing social norms. In addition to the mentally ill this number will include drug addicts and alcoholics.

"The question of how to tackle the formidable challenge of helping the world's disabled is not one of policies or approaches", says ILO Director-General, Francis Blanchard. "These exist, we have developed them. What is lacking, however, is the political will to act and—putting it quite bluntly—money.

"ILO experts have calculated that in order to help stem the tide, the world would have to find a minimum of 25 additional cents to spend on each disabled person annually—or in total some $100 million a year.

"This at least would help to establish pilot vocational rehabilitation programmes in those countries where no such services exist; equally important, it would provide the means to set up some sub-regional and regional training centres where much-needed specialized staff could be trained.

"It is a modest, realistic goal", Mr. Blanchard adds. "And if the term human dignity has any meaning at all, these 25 cents should certainly be found."

■ **Ed. Sackstein**

KIDS ON THE BLOCK

Renaldo Rodriguez, 10 years old, is almost totally blind; Mark Reilly, 11 years old, has cerebral palsy and gets around in a wheelchair, his "cruiser" as he calls it; Melody James, 9 years old, suffers from nothing more than short-sightedness and is very curious about her more severely handicapped friends. All three (inset), together with Ellen Jane, 17 years old, who has Down's Syndrome and works as an assistant to a veterinarian, and Brenda Dubrowski, 10 years old, a "normal" child with a weight problem (pictured performing below), plus Mandy Puccini, 12 years old and deaf (not shown), are members of an amazing troupe of puppets whose purpose is to help children to develop positive attitudes towards people with disabilities. Created by Barbara Aiello, a former teacher of handicapped children and a writer on special education, the "kids on the block" are three feet tall and wear real children's clothes and shoes. Mrs. Aiello believes that "children will talk more readily to puppets than to adults or even to other children" and that the integration of handicapped children into regular classrooms fails less often because of their disabilities than because of the other children's attitudes. "Kids on the Block" has two important goals. "First", says Mrs. Aiello, "I want to teach children about handicaps in a non-threatening fashion. Second, I want to show non-handicapped children how to develop positive relationships with their handicapped peers. The puppets show them how they can be friends."

Photo Marcel Salvaro, Unesco

Photo inset © Kids on the Block, Inc., Washington, D.C.

Disabled characters in search of an author

by Tordis Orjasaeter

Photo Laurence Brun © Petit Format, Paris

IT is important for handicapped children to meet themselves in children's books, to see pictures and read about children like themselves, their lives, problems, feelings, circumstances. And it is important for other children to get acquainted with handicapped children, since an unfortunate segregation policy in many of our countries has for decades placed many handicapped children outside our neighbourhoods. It is thus all the more necessary that we meet them in books to prepare the soil for integration.

Mentally retarded, physically handicapped or other disabled children almost never see children like themselves on television or in films, unless the programme specifically concerns handicapped children. They almost never belong to their environments in the mass media as naturally as other children do. If one never reads about anyone like oneself or meets anyone like that in television or on the radio, it is a sort of affirmation that one is not good enough or does not belong anywhere or has no value.

During the last decade quite a few books have appeared about handicapped children, but many of them are not good enough. They often activate our mechanisms of rejection and make integration even more difficult. Because literature influences us for better or for worse, especially when we are children, it is important to evaluate it critically. So many books are well-intentioned, and their authors have surely tried to encourage understanding, and yet the results are disappointing.

There is the hidden rejection found in many well-intentioned books where healthy

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TORDIS ORJASAETER, *of Norway, is associate professor at the Norwegian Advanced College for Special Education, and the author of several books on children's literature. The present article has been extracted from "The role of children's books in integrating handicapped children into everyday life", a background paper prepared for the Seminar on Books and Disabled Children organized by Unesco in co-operation with the Bologna Children's Book Fair in April 1981.*

young people who meet handicapped persons are filled with gratitude for their own good health. The underlying attitude is that the normal thing is to be healthy, beautiful and charming—and the handicap somehow is a kind of punishment for our sins.

In children's books about handicapped children we frequently find a certain principle of compensation so heavily stressed that it constitutes a hidden sort of rejection: blind people who automatically, almost by virtue of their blindness, are so exceptionally kind and good and have such a good ear for music; or the brave boy in a wheel-chair.

The blind characters in children's books are mostly girls—it seems so suitable that girls should be sweet and gentle and play the piano. The characters in wheel-chairs are mostly boys, extraordinarily clever boys, the best companions anyone can think of and such excellent referees in a football or baseball game. The handicap is compensated far beyond reasonable limits.

One might say that such books provide a certain degree of information about the handicapped. But on the whole they give a false picture. A handicap does not automatically make anyone into an extraordinarily fine person. The opposite pattern of rejection is heavily utilized in cheap serial literature, in which most frequently the villain is physically handicapped. This kind of reading is a hothouse for discrimination against the handicapped.

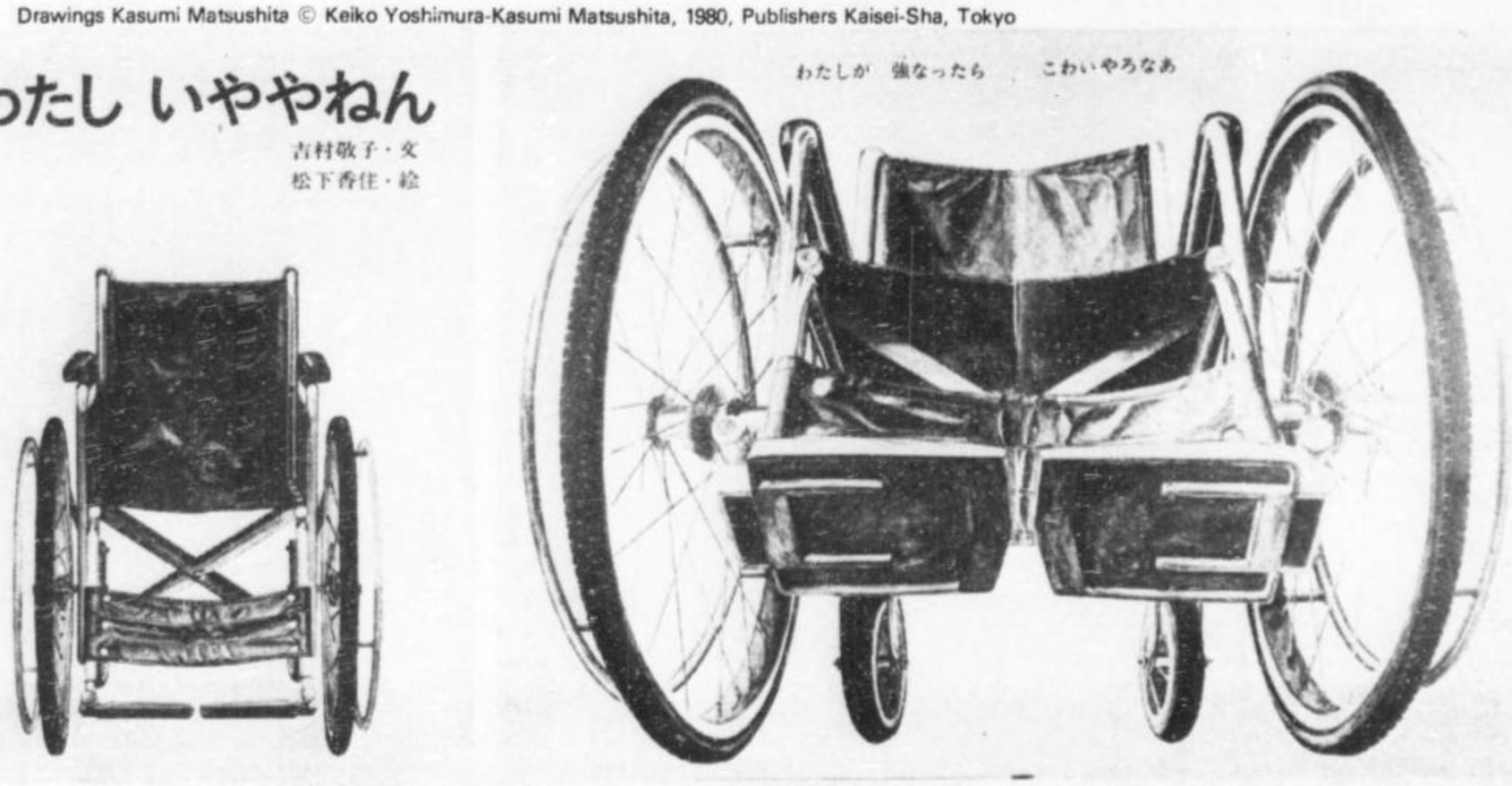
There are so many misleading books about mentally handicapped children. Some typical examples: many authors use the description *ill* when they write about mentally retarded children. They are not ill, no more than other children unless they have measles or colds or something like that. They are not ill, they are retarded in their mental development.

Other authors tell us that an autistic child can suddenly become normal if his brother is kind to him, or a girl stops stuttering if she gets a pet, and another boy starts talking when he gets a friend, although he has never been able to talk before. Such things may happen, but very rarely. Handicapped children do not become "normal", they just become grown-ups.

The most common pitfall is to concentrate only on the handicap and make handicapped children very special. The truth is of course that a child with a handicap is first and foremost a child.

We need books containing good psychological descriptions of the handicapped person as one of the main characters and books where handicapped children belong to their environment as naturally as do other people. Happily, books exist in which the author shows both insight and poetic power. A typical feature of many of these books is that the author himself states that his books are written both for children and for adults. Many of these authors have experienced a handicap, either personally

Drawings Kasumi Matsushita © Keiko Yoshimura-Kasumi Matsushita, 1980, Publishers Kaisei-Sha, Tokyo



The Disabled are People Too **is the title of a recently published book in the form of a poem by twenty-five-year-old Keiko Yoshimura, who was stricken with cerebral infantile paralysis at the age of fourteen months. It is a frank account of what it feels like to be physically handicapped and confined to a wheelchair. The book is entirely illustrated with striking black and white representations of a wheelchair, the work of Keiko's long-time friend, artist Kasumi Matsushita.**

THE DISABLED ARE PEOPLE TOO

If I am honest with myself
I admit
I don't like going out

I like people
But I hate crowds
I hate places where there are
likely to be crowds

Amusement parks are not fun
for me
Department stores are hell
In cinemas I am a nuisance

If I am honest with myself
I admit
I don't really like going out

If people stare at me
I hate it
If people pretend I am not there
I hate it

But why should I feel this way?
I am "people" too
I am not a creature from another planet

I am not a freak either
I don't have to hide away

I have an appetite for life,
I enjoy good things to eat and drink
I enjoy feeling

I sleep, dream and wake
I think, laugh and cry
I enjoy feeling

Why do people stare at me?
or look away from me?
Why do they treat me differently?

My heart behaves normally
it beats as it should
It is quite ordinary

The disabled are people too

All people are different
What is so special about my difference

A friend warned me
Be strong, be brave, she said

I thought about being strong and brave
What did being strong mean to me?
If I am not strong now
how should I become strong?

If I need to become strong
there must be a way

How would I change
If I were strong?

Would amusement parks be fun?
Would I enjoy department stores?
Would I like crowds?

A friend warned me
Be strong, be brave, she said

I don't understand becoming strong
Perhaps being strong
is not for me

If I were strong
People might be afraid of me

Better by far that I be brave
People will still stare at me
or look away from me
But if I am brave I shall not mind

Keiko Yoshimura

or among their children, friends or neighbours.

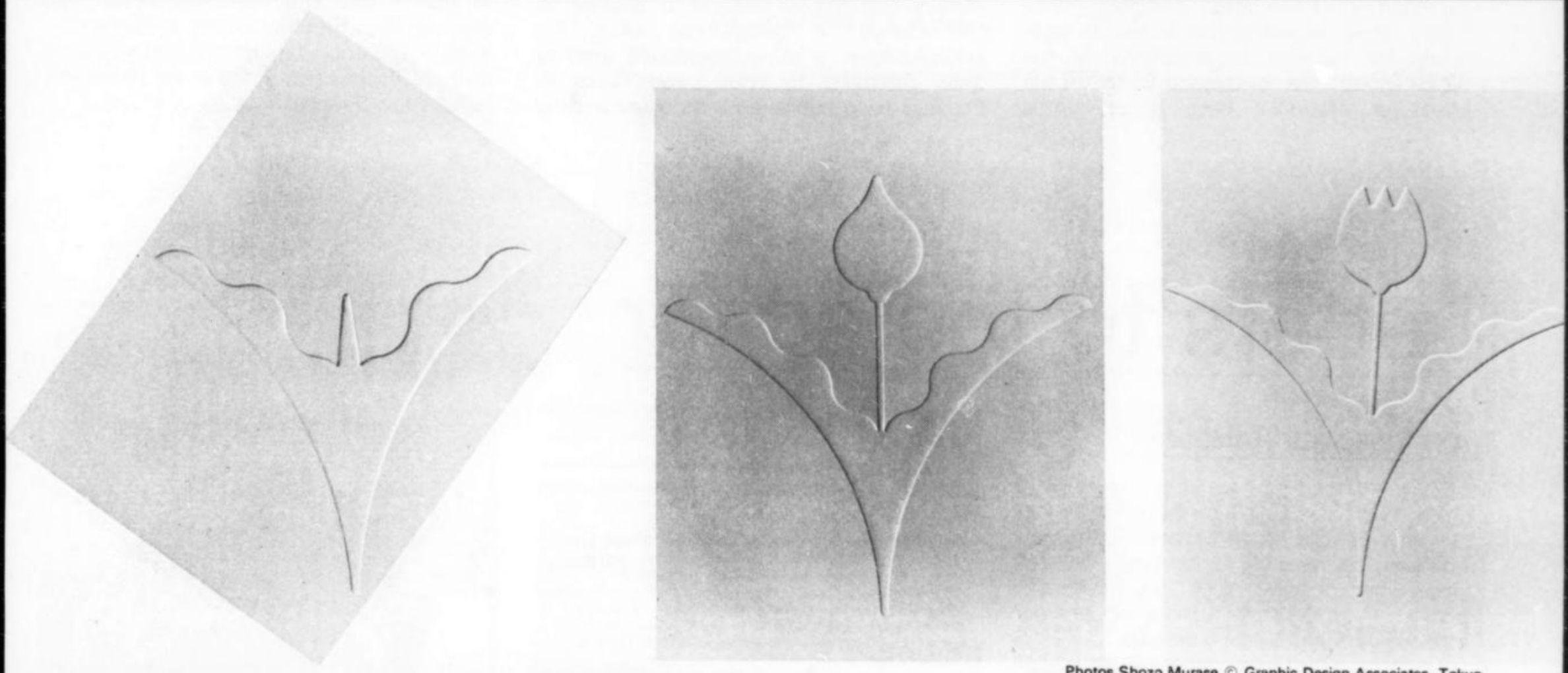
Most children's books about the handicapped tell us about children with physical or sensory handicaps, and the authors' intention is quite obviously to make the readers identify themselves with these children. Books about mentally handicapped children are fewer in number and mostly written from the point of view of a sister or brother.

During the last decade we have seen a number of photographic picture books about handicapped children. Children who read them are usually as fascinated by this documentary material as by fiction. It acquaints them with handicapped children in their daily life. Such books are often excellent for handicapped children as well; they can look at pictures of and read about children who look like themselves and have to struggle with some of the same frustrations.

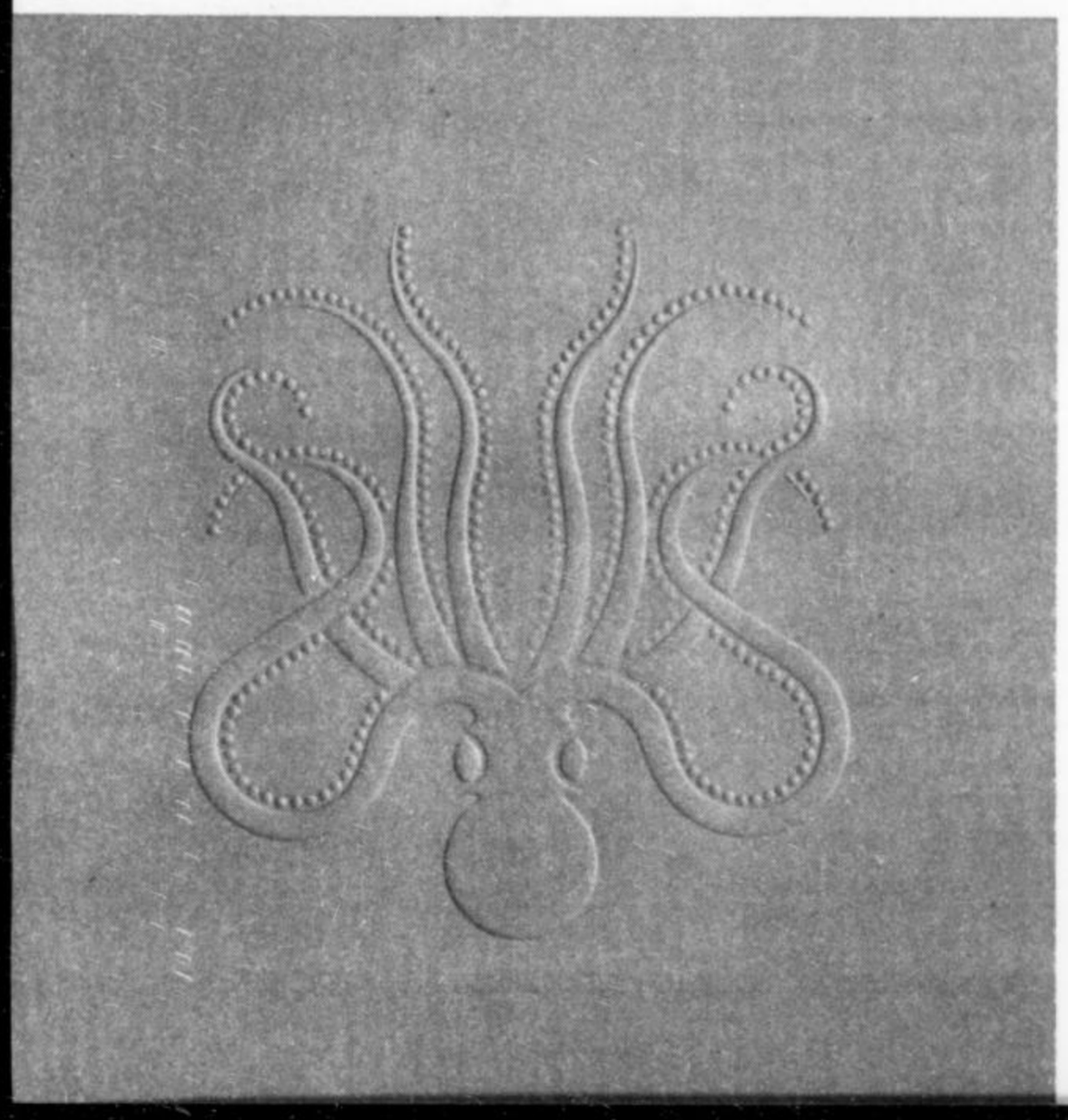
Especially interesting are picture books made by authors or artists who are themselves parents or siblings of handicapped children using their personal experience and love, trying to tell other children how it can be for a family to have a handicapped son or daughter, sister or brother.

In many cases it is a relief to read about the experiences of others. It can be a help towards seeing one's own situation in a wider perspective. There is comfort in knowing that others have been through the same experience, even if their conditions and situations in life are utterly different. For some people fiction can be an inspiration towards giving new insight, awareness and acceptance.

■ **Tordis Orjasaeter**



Photos Shozo Murase © Graphic Design Associates, Tokyo



Picture books to be seen with the hands

Why are there so few books for the blind with pictures that can be "seen" with the hands in the same way Braille texts can be "read" with the finger-tips? This was the question that inspired Japanese designer Shozo Murase to produce a five-volume work in which the illustrations are in relief. The illustrations on this page are from the volume which aims to give blind children an understanding of the shape of things in nature and of how they change during the four seasons of the year. Photos above, the development of a tulip; left, an octopus.

UNESCO NEWSROOM

Unesco Clubs support IYDP worldwide

Unesco Clubs—totalling some 2,500, in 78 countries—are supporting the International Year of Disabled Persons (IYDP) with a wide range of initiatives linked to the needs and cultures of the communities to which they belong.

Their efforts are proving to be particularly effective in publicizing the objectives of IYDP. Many Clubs, notably in Belgium, Spain, the United States, France, India, Japan, and Mauritius, have devoted all or part of their newsletters to articles on IYDP themes, as well as producing and distributing posters, tracts and other documents.

A sample of IYDP-linked activities by Unesco Clubs around the world: in *Morocco* the Federation of Unesco Clubs has launched an information campaign in a dozen cities, including film shows to raise funds for national organizations of the handicapped. The 80 Unesco Clubs on the island of *Mauritius* have drawn up a questionnaire on the situation of the disabled to help in understanding their problems and needs. A similar approach has been adopted in *India.* The Mangalore Club, for example, has carried out a survey among handicapped persons in one of the villages it has "adopted", as a prelude to action on their behalf. Also in India, the Nagpur "friends of Unesco" have held a public seminar on handicap and donated medical and other supplies to local centres for the disabled. In *Gabon*, an "IBOBU" Club *(Ibobu* means "handicapped" in a Gabonese dialect) has been created. In *Japan,* the Federation of Unesco Clubs, which groups some 450 associations of clubs for adults and young people, has launched a nation-wide fund-raising effort for Unesco's Co-Action Programme (see page 15) and in *Italy* the Unesco Centre in Florence is extending to disabled children its work on behalf of literacy teaching for children in hospital. In the *Congo*, a competitive game for schoolchildren is being ingeniously used to draw attention to IYDP, and Clubs in Ecuador have published a brochure ending with the question; "What can *we* do to help?"

Unesco to issue bibliography on handicapped children

A worldwide survey of reading materials for and about handicapped children has been prepared for Unesco by the International Youth Library (Munich) and will be published later this year.

A broad selection of titles, each followed by a brief description in English, is presented by country, language, author, reading age and type of handicap. The books listed include those for handicapped children and young adults, children's and young people's books about the handicapped, and publications for young adults that help to illuminate the special problems of the handicapped. The bibliography will be available in the latter part of 1981 and may be obtained upon request from Unesco, Division for Book Promotion and Encouragement of International Cultural Exchanges, 7 Place de Fontenoy, 75700 Paris (France).

Letters to the editor

EPILEPSY — A NEGLECTED HANDICAP

Sir,

The term *handicap* describes a very wide range of conditions. In common parlance, however, its meaning is extremely limited since when people talk of "the handicapped" they are generally thinking of persons afflicted with a physical handicap.

And yet those who suffer from other kinds of handicap are also handicapped persons, who face the problems of finding a place in society. Moreover, the non-physically handicapped often find their problems all the more difficult to bear because others find it hard to accept their existence. Here is an example of what I mean. An employer will not create too many obstacles in taking on a one-armed person or a handicapped person confined to a wheel-chair, but he will refuse outright to employ an epileptic capable of producing work of an equal quality.

I have been epileptic for 18 years. It is impossible for me to find a job, in other words to live like other people, simply because I am labelled "epileptic"—a word which causes apprehension for being too little understood.

And yet there has never been any question of ignoring the work of Flaubert, Molière, Dostoevski, Maupassant, Caesar, and many others simply because they were epileptics. (Needless to say, I am not presuming to compare myself with *them!)*

I am convinced that providing the public with precise information about epilepsy, a form of nervous illness which originates in the brain but has nothing to do with insanity, would lead to much greater social acceptance of epileptics and would further their integration into society.

Yves Dupin
Bordeaux
France

BRINGING THE WORLD TO OUR FINGERTIPS

Sir,

I wish to express the heartfelt gratitude and pleasure I felt on receiving the *Unesco Braille Courier*. Your magazine, in addition to its cultural importance, offers us, the blind, a unique opportunity to learn about the international situation. Please put me on your list of subscribers.

Antoine Tchaby
Littoral Province
Cameroun

A SELF-IMPOSED HANDICAP?

Sir,

Your January issue on the handicapped is almost entirely devoted to "noble" handicaps. When can we expect to see a cover showing a child suffering from Down's Syndrome? Or, where the misfortunes of the innocent are concerned, are your attitudes moulded by an unconscious (or shrewd) racism?

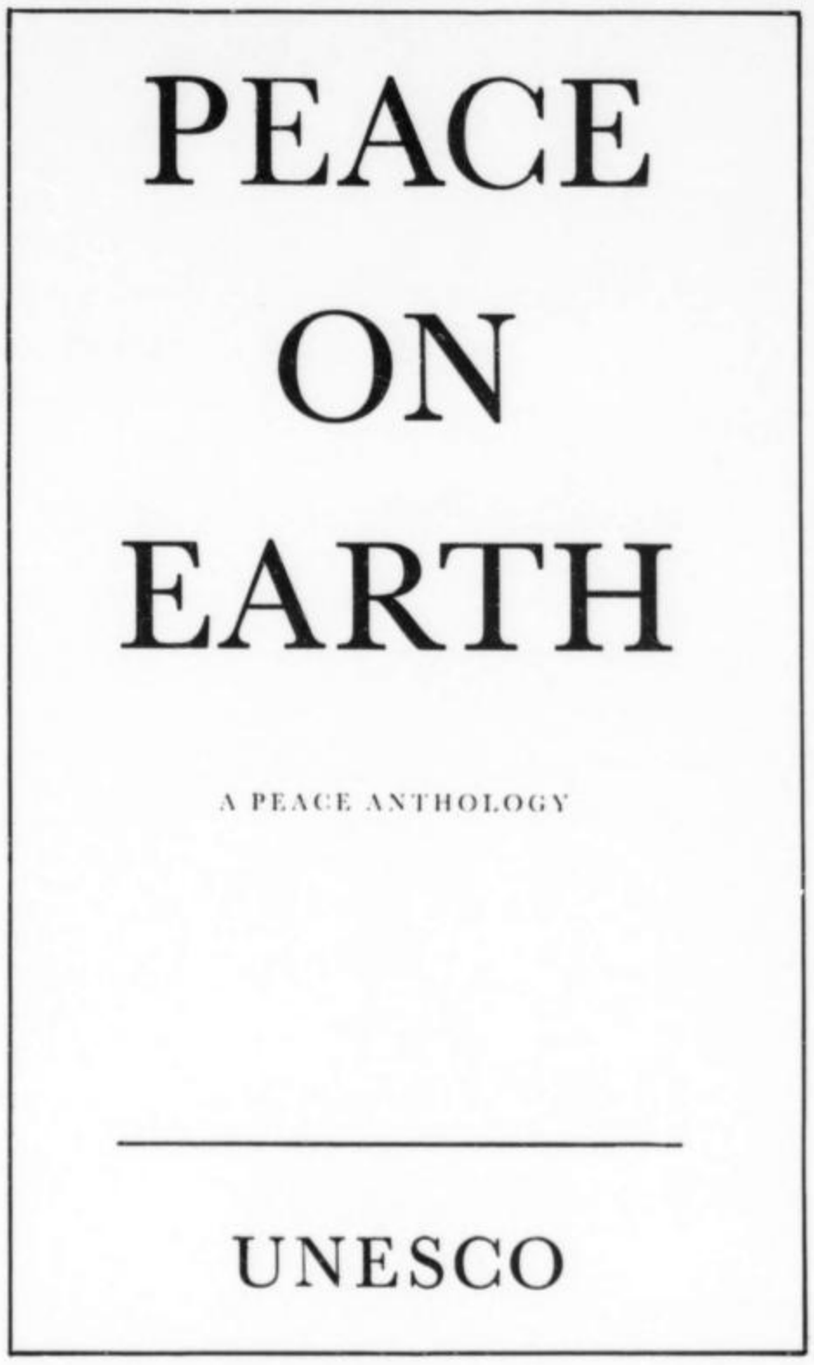
Georges Leugé
Rouen
France

The boundaries on this map do not imply official endorsement or acceptance by Unesco or the United Nations.

CORRECTION

Part of the outline of the map of Yugoslavia which appeared on page 16 of the November 1980 issue of the *Unesco Courier* should be rectified as indicated above. Because of its reduced scale, the corrected drawing of course only provides a broad indication of the boundary line.

BRODARD GRAPHIQUE. COULOMMIERS - Dépôt légal C 1 - June 1981 - IMPRIME EN FRANCE (Printed in France)



Peace on Earth is a selection of writings, some famous, some less familiar, through which men and women from different cultures, speaking different languages and holding different opinions, have described what seemed to them the possible ways to peace. These texts, from many historical periods and all the world regions, echo the age-old aspirations of humanity to peace and understanding between peoples. Contents include :

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- **Voices raised against war through the centuries**
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Good vibrations

The question of whether handicapped children should be educated in special institutions or integrated, more or less completely, into the ordinary school system is today giving rise to widespread debate. Photo shows two pupils, one of whom is physically handicapped, in a Paris school.

Photo Laurence Brun © Petit Format, Paris